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The Experiences of Adolescents with Type 1 Diabetes

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Doctorate in Clinical Psychology

The University of Edinburgh

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Table of Contents

<u>Section</u>	<u>Page Number(s)</u>
Table of Contents	3
Abstract	4-5
Systematic Review	6-35
Bridging Chapter	36-43
Aims	44
Method Section	45-52
Journal Article	52-76
Additional Results	77-99
Additional Discussion	100-112
References	113-120
Appendices Table	121
Appendices	122-166

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Abstract

Introduction

Type 1 diabetes is a condition which affects the lives of thousands of young people throughout the UK. Existing research has recognised the difficulties that adolescents have in managing their diabetes, and a large amount of research has focused on glycaemic control, and influential factors. This project attempted to establish what is known about young people's experiences of living with type 1 diabetes, and to further develop this knowledge pertaining particularly to the school environment through qualitative research.

Method

A systematic review of the literature in relation to young people's views of their life with type 1 diabetes was conducted and a synthesising thematic analysis was carried out. A qualitative research study was then carried out involving 7 adolescents aged 13-16 years who had a diagnosis of type 1 diabetes. Semi-structured interviews were carried out with the focus being on the young people's experiences of type 1 diabetes within the school environment. Interview sessions were transcribed and Interpretative Phenomenological Analysis (IPA) was used to analyse the data.

Results

Five themes emerged from the systematic review. Analysis of the studies led to the emerging themes of: Normal/Different, Control/Management, Relationships, Health-care and Educational experiences. The articles revealed that the experiences of adolescents varied, and were frequently dependent upon the actions of others. Four major themes emerged from the analysis of the research study: Support, Knowledge and Understanding, Standing out, and Adjusting and Accepting.

Discussion

Systematic review of the articles revealed that the experiences of adolescents varied, and were frequently dependent upon the actions of others. A sense of normalcy was important, and the strict routine and activities of diabetes management impacted upon their ability to achieve it. The support of friends and family was valued, but could at times become overwhelming and educational and health professionals made a difference to their ability to successfully fit diabetes into their lives. The suggestions made by individuals within the studies were generally consistent, and have implications for healthcare providers, friends and families, and schools in relation to facilitating successful diabetic management. Many of the young people taking part in the present research study had encountered negative experiences within the school environment in relation to both peers and staff. However, they described elements of helpful practice and made suggestions for improvements that could be made within school to facilitate a more positive experience.

Running Title: Adolescent experiences type 1 diabetes.

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Experiences of adolescents with type 1 diabetes: a systematic review of qualitative studies.

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Abstract

Aims: A systematic review was conducted to explore what is known about adolescents' views of living with type 1 diabetes.

Method: Electronic databases were searched for qualitative studies involving adolescents with type 1 diabetes. Following quality appraisal 10 articles were included in the synthesising thematic analysis.

Results: Five themes emerged from the analysis of the studies; normal/different, control/management, relationships, health–care and educational experiences. The articles revealed that the experiences of adolescents varied, and were frequently dependent upon the actions of others. A sense of normalcy was found to be important, and the strict routine and activities necessary for diabetic management impacted upon adolescents' ability to achieve it. The support of friends and family was valued, but could at times become overwhelming and unhelpful, no matter how well meaning. Educational and health professionals' actions also made a difference to adolescents' ability to successfully fit diabetes into their lives.

Discussion: A number of quality and procedural difficulties were identified within the studies, and these would best be addressed by further research in the area involving larger sample sizes and more diverse populations. The suggestions made by individuals in certain studies were generally consistent, and have implications for healthcare providers, friends and families and schools in relation to facilitating successful diabetic management.

Keywords: Adolescent – Qualitative research – Review, systematic – Type 1 diabetes mellitus

Introduction

It has been identified that throughout Europe there is an issue with glycaemic control in young people with diabetes (1, 2). Given what is known about the impact that lack of control over diabetes can have on physical health, it is reasonable that a major focus of diabetes related research thus far has related to factors influencing control.

Studies have used monitoring of levels of HbA1c to identify factors that mediate the degree of control people have over diabetes. Findings suggest a number of variables that impact upon children's diabetic control including: life stress, regimen adherence, perceptions of locus of control and the onset of adolescence (e.g. 3, 4).

A large amount of research into children with type1 diabetes has understandably focused on the role of family relationships in its management. Families play a significant role in the management of a child's diabetes, and it has been labelled a 'family disease' (5). Adherence has been found to be related to family experience, with conflict around management of diabetes increasing the likelihood of poor health outcomes through poor glycaemic control (6).

Interventions which have been shown to benefit young people in managing their condition have not always been found to appeal to them (7). There could be a number of reasons for this discrepancy, but in order to find ways of better supporting young people to manage diabetes in ways that fit into their lifestyle it is necessary to find ways of understanding their everyday experiences.

A previous systematic review in the field (8) was conducted to explore the causal factors of deteriorating metabolic control in adolescents with type 1 diabetes. They identified that social relationships are key for young people in managing diabetes and found that managing the demands of diabetes in different situations was difficult. The authors recommended that further qualitative research with young people was conducted to enable a better understanding of their experiences of living with type 1 diabetes.

A systematic literature review of the experiences of adolescents with type 1 diabetes was conducted. The aim of this review was to explore what is known about young people's perspectives of living with type 1 diabetes. This study differed from the previous review as it was exploratory rather than focusing on causality and looked at studies outside of the USA which had differing healthcare and educational experiences.

Method

Search method

Electronic databases were searched using the term (“type 1 diabetes” OR “diabetes mellitus”) AND (“experiences” OR “perceptions” OR “views”) AND (“adolescent” OR “teenage” OR “young people”) AND “Qualitative” for the period of 1997 to current. Databases searched EBSCO host, OVID, Web of Science, Emerald, Proquest, and Science direct. Qualitative studies of the experiences and views of young people age 13-20 years with type 1 diabetes published in English were included. Searches identified 2,825 studies, including duplicates. After screening the titles and abstracts for relevance, 21 papers were selected. The full text of the papers was examined against the inclusion criteria. Quantitative studies were not included, and studies including participants younger than 12 or older than 20 were excluded. A total of 10 studies remained.

Quality appraisal

All of the studies were systematically evaluated using the appraisal tool of the Critical Appraisal Skills Programme (CASP) (9) (see Table 1). All of the studies met in excess of four of the standards and were therefore accepted in the review, the studies varied in quality and this was considered when utilising the evidence.

Synthesis of the studies

Synthesis of the studies was undertaken using thematic analysis to identify prominent or recurrent themes. Descriptions from the studies within the identified themes were then integrated into the review.

Results

The studies were based in a variety of countries. The majority of the studies (n=6) were based in the USA (14 -19), although two were in Sweden (10, 11) and a further two in the UK (12, 13). Two of the studies (12, 16) focused on diabetes in the educational environment, one looked at parental conflict (18), another looked at experience of diabetes services (13) whilst the remaining studies looked at experiences in the wider sense (10, 11, 15, 15, 17, 19).

Study samples

The sample sizes of the studies ranged from 4 to 32 participants. All of the studies targeted a specific population in their sampling method, three of the studies reported purposive sampling (14, 15, 16), four used convenience sampling (10, 11, 17, 18), and the sampling method of the other studies (12, 13, 19) was unclear. The studies all recruited young people diagnosed with type 1 diabetes.

The participants were aged between 12 and 20 years, and were recruited from a variety of sources including local diabetic clinics (11, 13, 14), diabetes summer camps (15, 18) and local physicians' offices (19) as well as from participants involved in larger studies (16, 17). The origin of the sample in two of the studies was not clear (10, 12).

Study Methods

Interviews were the primary method of data collection in the studies, with 5 studies (10, 11, 14, 15, 16) involving face to face interviews with the young people, and another employing telephone interview (12). Other studies used group discussion methods (17) or more formalised focus groups methodologies (13, 18, 19) of data gathering.

Analysis style

A phenomenological approach to data analysis was the most popular (10, 11, 15) although differing techniques within that approach were used. Content analysis was used by two of the studies (16, 17) who used Miles and Huberman's (22) approach facilitated by use of NVivo software. A focus group analysis was used in one study (18) whilst another (19) used a five step qualitative analysis approach. Two studies (12, 13) undertook thematic analysis using winMAX software. The remaining study (14) used a Constant comparative method (23) and Miles and Huberman's (22) analysis.

Systematic Review Findings

A number of themes emerged from the articles as detailed in Table 2. Some themes were evident in a number of the papers (n = number of papers in which the theme emerged). Those themes were:

- A. Normal/Different (n = 8)
- B. Control/management (n=8)
- C. Relationships (n=7)
- D. Health care (n=8)
- E. Educational experiences (n = 8)

Evidence for each of the themes varied in credibility dependent on the quality of the study from which it emerged (see Table 1). However, each theme is evidenced by some high quality research, and is thus sufficiently robust to justify the overall conclusions drawn.

Themes

A. Normal/Different

This theme emerged in 8 of the studies (10-15, 17, 19) under a variety of titles (see Table 2). Throughout these studies, the experience of having diabetes came with a sense of being different for a number of adolescents, and given the developmental stage there was a desire for ‘normalcy’ and to fit in with peers.

For adolescents the experience of having and managing diabetes was not seen as being typical, however, in two of the studies (10, 19) it was found to be viewed somewhat positively e.g. maturing faster (19). However, the majority of the experiences relating to feeling different were found to be negative (10, 12, 14, 15, 17, 19).

Two studies (12, 14) discovered that young people felt different due to being unable to do things peers could, as a result of their diabetes; e.g. going to evening events or eating out with friends. Another study (15) found that it was important to the adolescents to be actively involved with the adolescent culture, and that they felt that diabetes sometimes made them stand out from the crowd.

One study (19) established that some adolescents felt different because of their parents’ responses to their diabetes e.g. preventing them from spending the night

with friends for fear of diabetic emergencies. Whereas, in another study (10) it was the adjustments that the adolescents had made to their lives in order to manage their diabetes that were identified as highlighting their sense of being different. This feeling of difference and related embarrassment even led to findings that young people would consider; not engaging in their diabetes self-care (10, 13), concealing care issues (17), or keeping their blood glucose high (12) to temper the issue.

B. Control/management

Eight of the review studies (10-15, 17, 19) reported descriptions within the theme of diabetic control or management under a variety of headings (see Table 2). Diabetic management was found to be a challenge for adolescents in respect to the control it exerted and the responsibility it required them to undertake (15). In fact, taking responsibility for diabetic management was a theme which emerged in a number of studies (12, 14, 15, 19). One study (14) reported that a number of adolescents recognised a point in time when they felt a desire to learn more about diabetes and become more independent. Another study (19) discovered that participants felt a desire for greater independence from their parents, and other adolescents (11) believed that independence would be more possible if they listened to and learned from the diabetic team. For adolescents in three of the studies (10, 11, 17) there was a distinct sense of achievement in being able to manage such a complex condition, and being able to do so independently was important to them in allowing them greater flexibility in their lives.

Participants in the one study (17) expressed a growing confidence in their self-management and the positive impact upon it had had upon their lives. Other

adolescents (19) supported this perspective, and reported having a better understanding of their bodies, the importance of healthy eating and exercise, and being able to recognise their own warning signs and adjust their regimen accordingly.

A more negative experience described by some adolescents in one study (19) was the out of control feeling that came with having diabetes, illustrated by one young person's description, *"I think it is just that you don't have any control. Diabetes always has a hold on you. You don't take your medicine because you don't think it will hurt you-then you get sick."* (p245).

The self-care routine was often discovered to be an area of difficulty for young people (10, 13, 14, 19). Adolescents (15) considered the disruption to their lives that came with strict and rigid routines to be problematic, whereas for others (e.g. 13, 14) the problem was the monitoring and recording, food intake, administering insulin, and the boring and intrusive clinic reviews. The need to always plan which limited their opportunity for spontaneity also emerged as a source of frustration (10, 12, 14), as was the impact it had upon social opportunities (14).

C. Relationships

7 studies reported adolescents' experiences in regard to relationships with the people in their lives. Relationships were discussed in seven of the reviewed studies (10, 11, 14, 15, 17-19) under a number of headings (see Table 2). One study (17) found that young people believed diabetes had strengthened their relationships with friends, and were positive about having people around who cared and supported them. Another

(11) recognised that young people felt supported by friends who were willing to fit diabetes into their lives too e.g. buying low sugar food, and consequently were able to forget about their diabetes when out with them.

The benefit of letting friends know about their diabetes was described in four of the studies (11, 14, 15, 19). One (14) found that telling friends gave adolescents a sense of security and a 'back up system', while in two studies it was more about having friends know what to do if they became unwell (14, 19).

Experiences with parents were viewed positively by participants in a number of the studies (10, 11, 17-19). Parental support was viewed as helpful when it was perceived as tangible (17), or problem solving in nature (11). There was a perception that parental support reduced the pressure on the adolescents; e.g. working alongside a parent to manage their diabetes (14); and parents providing reminders about their self-care (11) were described as helpful.

Parents who were validating or emotionally supportive of the adolescents with diabetes were described positively (11, 14, 18, 19). Weinger *et al.* (18) discovered that adolescents appreciated parents who provided reassurances about the difficulties associated with the complex nature of diabetes, and its complications. They (18) also found that parental relationships were viewed most positively when parents were calmly reassuring in helping them to manage their diabetes whilst still meeting the challenges of adolescence.

Young people in two of the studies (10, 16) reported positive experiences with sports coaches. This was discussed in relation to the important role coaches had in the

process of liberation from parents. Some adolescents described how coaches supported them in taking care of themselves, giving them a feeling of security (10).

Whilst relationships with the people in their lives were seen as positive at times, adolescents in 7 of the studies described other more negative interactions (10, 11, 14, 17-19).

Friends' behaviour emerged as a source of additional stress; being insensitive at times e.g. offering them sugary foods (15) or asking intrusive questions in social contexts (17). Adolescents were also frustrated by friends who planned social activities which were difficult for them due to their diabetes management (14).

Adolescents were discovered to describe their friends as nagging at times e.g. telling them what and when to eat (10), or over protective (17, 19); for example, "*my best friend acts like my mom. It gets on my nerves*" (19, p248), and others worried that their peers might tell other people about their condition (17); all unhelpful experiences.

Parents' behaviour was also felt by adolescents to be unsupportive at times (10, 11, 15, 17-19) specifically when parents were: over protective (17, 19), hyper-vigilant (15), and being over concerned (17). In Weinger *et al.*'s (18) study one participant said, "*the first year I got diagnosed, my parents asked me so many times, 'are you ok? What are you?' and so they made a rule that they can't ask me more than once a day each parent. 'cause I was going crazy.*"(p332).

Another source of stress which became apparent from some studies (10, 15, 17, 19) was parents who were perceived as 'nagging' e.g. dictating their diet (19). Such behaviour was resented by adolescents who felt it was "annoying" and demonstrated

parents viewing them as ‘diabetics’ rather than individuals (18). Nagging was unhelpful as it had little, or even a negative impact upon adolescents’ diabetes management (11). Although seen as stressful, adolescents in some studies conceded their parents’ nagging might be a sign of their caring (10, 15). There would therefore appear to be a fine line for adolescents between parents being supportive, and being pushy and unhelpful.

Parents’ responses to difficulties with their diabetes management, or poor blood measurements were described in some studies as being unhelpful; lacking in understanding or blaming (15, 18). One adolescent described, “*my dad’s still like a control freak and, I mean, if you’re like 240, he’s like ‘what did you eat? You broke all the rules...’*” (18, p332). Being over emotional in response to unsuccessful diabetes management such as yelling (15), becoming upset (11), “flipping out” (18) or being openly disappointed (13) also emerged as a common issue for study participants, who recognised that they responded unhelpfully when faced by negative emotional responses from parents (11).

D. Health care

Eight of the review studies (11-17, 19) reported descriptions within the theme of health care under a variety of original theme headings (see Table 2). Young people (11, 13, 17, 19) expressed some concerns in relation to their health care, with confidence regarding care plans emerging in a variety of studies. One study found that adolescents lacked confidence in their plans and felt they should be given more input in developing them (17). In another study (11), adolescents recognised that providers had knowledge in relation to diabetes, but did not believe that they

understood them as people and therefore they felt that care plans were not recognisant of their lifestyles. Others described feeling happier when they were supported by professionals to live life in a way that worked for them rather than being 'fed information' (19).

Interactions with healthcare professionals were discussed in a number of the studies (11-17, 19); with participants describing interactions as being either helpful or negative. Views also differed depending on the professional being described; with nurses generally receiving more positive regard (13, 16). Positive experiences with professionals were described in studies when providers made a connection with young people (15), offered validation of the challenges they faced (14), gave positive feedback regarding self-care skills (17), encouraged them to make individual decisions (11), or included them in the consultation (15).

Nursing staff were generally described positively; as being supportive of the young person and his or her family and as having a realistic approach to diabetes management (13), and being knowledgeable (11). Some doctors were also seen in a positive light especially those who took an interest in the person as well as their diabetes (19). However, for young people in a number of studies, such an experience was unfamiliar (13, 17, 19), having experienced interactions as rushed and formal, and attempts by doctors to ask about their personal life to be uncomfortable especially if they did not feel the doctor was genuinely interested (13). Adolescents in some studies felt that doctors treated them not as a person but as their disease (19), and were more concerned about their medical results than them as people. Consultations were a negative experience for adolescents who perceived them as being primarily about gathering information and measurements (13) and

professionals were also perceived as reacting to unsuccessful management in a critical and unhelpful manner (17).

In two studies (17, 19) participants made suggestions about how professionals working with them could improve their care, for example *“listening to what us kids have to say”* (17, p77), and *“look at each age group that you are dealing with”, “don’t just threaten your patients-just try to help them get it [their diabetes] under control”* (19, p249). It was also found that some adolescents would have liked to be able to express these views to their health care providers, but did not, for fear it would be difficult or might anger professionals (17).

E. Educational experiences

Educational experiences were described by participants in 7 of the studies under a variety of different headings (10, 12-17, 19; see Table 2). Positive experiences in the school environment were described by participants in a number of studies (14-16), including thoughtful staff (16), and the opportunity to assert independence from families provided by school trips (14). Unfortunately those experiences were less common in other studies (10, 12-16, 19), who discovered that adolescents generally found managing their diabetes at school to be a stressful experience, particularly in relation to teachers’ knowledge and peers understanding.

Finding a balance between diabetes management and education was difficult for young people (12, 13, 19). In a study of students’ experiences with diabetes (12) it was found that balancing demands was difficult due to time factors and inadequate support from staff. Times of transition such as transferring schools also emerged as

being stressful due to the need to build up care relationships and routines at the same time as going through typical adjustments faced by other adolescents (17).

A somewhat concerning trend that emerged from a number of studies was the belief of adolescents that their teachers lacked knowledge about diabetes (13, 14, 16, 19). A number of studies (13-16) also discovered that adolescents had experienced insensitivity by teachers in relation to their diabetes; with teachers providing sugary treats as rewards (13, 16), and behaving in ways that made them feel like they stood out (10). More worryingly, this lack of knowledge was understood to have led to necessary diabetic management being forbidden, e.g. prohibiting food or drink in the classroom (16), or occasions where diabetic incidents were unsuccessfully managed (13).

Discussion

The ten studies of adolescents' experiences of diabetes reviewed in this article were based on research conducted in three different countries and offered a picture of some typical experiences. The articles revealed that the experiences of young people with diabetes were varied; however, a number of consistent themes emerged. The theme of desiring to be normal was expressed within a number of the studies (14, 15, 17) by a number of the young people who participated. It emerged that feeling normal was made easier or more difficult depending upon the actions of others (11, 13-17, 19) such as peers, parents, health care professionals and teachers. Young people expressed that they felt unable to appear normal if their parents were overprotective and restricted social activities (10, 17, 19). This difficulty was compounded by the strict regimens imposed upon them by the need for diabetes management, particularly if their provider was not attuned to their needs as adolescents and the lifestyle of their population (11, 12, 17, 19). They also found it difficult to appear normal if friends arranged social activities which were contra to their management routine, or insensitively asked diabetes related question in social situations (15).

Peer support was seen as being particularly important to the adolescents (11, 14, 15, 17, 19); giving them confidence that they would be safe if anything should happen in relation to their diabetes. Friends who were able to adapt to the needs of the young person with diabetes were most helpful in enabling them to feel 'normal' (11). There

was a sense that the young people moved towards independence in their self-management as they moved through their adolescent years (14, 15, 19). This process was for some of the adolescents aided by people outside of their families such as friends and sports coaches (10, 16), but was also hampered at times by a lack of information, which had previously been given to parents in diabetes consultations (11).

The complicated and regimented management regime was an area of difficulty for a number of the young people, however, there was a sense of pride and accomplishment once a young person became able to self-manage all of their care, and this enabled them to have more flexibility within their lives. The educational environment was not experienced as being positive by participants in a number of the studies (10, 12-16, 19). Concerning experiences of being unsupported, singled out and even being prevented from carrying out necessary self-care emerged within that theme, as did the perception that teachers lacked knowledge about diabetes and more importantly perhaps, about what to do should a diabetic emergency arise.

Quality of the studies/Methodological limitations

Upon evaluation of the studies with the appraisal tool (13) (see Table 1) the studies met varying numbers of criteria. Two studies (11, 15) met 9 of the 10 criteria fully, one (16) met 8, two (18, 19) met 7, one (14) met 6, two (13, 17) met 5 and two (10, 12) met only 4.

All but one study (17) failed to explicitly consider the relationship of the participants to the researcher and the possible biases due to researcher role. Three of the studies (12, 14, 16) failed to fully justify the research design used. There was also some

disparity in the amount of detail given by the studies in relation to justifying the research method, or the choice of data collection method. Most of the studies (10, 11, 14, 15, 16, 17, 19) were, however, clear in their findings and discussed the contribution made by their research. There was a variety of different methods and analytical techniques used by the studies discussed within this review.

Some of the papers (10, 12, 17, 19) failed to detail sampling methods and at times there was a lack of clarity meaning that replication would be impossible, whilst some failed to provide sufficient evidence of methodological rigour (10, 12, 13, 14, 18).

As a result of analysis using the tool it was important that conclusions drawn were based upon evidence from the stronger quality studies (11, 15, 16) to ensure the quality of the systematic review. Any themes or conclusions which were presented in the poorer quality studies (10, 12, 13) but were not apparent in the higher quality studies were therefore not included in the results of the systematic review. However, evidence from poorer quality studies was used in addition to higher quality evidence to provide corroborative experiential evidence.

The implication of disregarding some of the unsupported thematic evidence from the poorer quality studies is that it is possible that useful information is lost. It is therefore recommended that further studies replicating the existing studies using more stringent methodology should be undertaken.

There was variation in the sample sizes used in the studies, with sizes ranging from a pilot study with just four individuals interviewed (14), to a larger interview study including 32 participants (11) and studies utilising discussions amongst small groups of young people with sample sizes from 6 (17) to 31 (19). Further research including

larger sample sizes would therefore be recommended; perhaps replicating the existing studies such as the pilot study undertaken (14).

It is possible that the group discussion methodology could limit the wealth of experiences gathered with less vocal young people's views being overwhelmed by other group members. Overall when comparing the studies using the group and the individual data collection methods there was a level of consistency; however, the groups in the studies tended to be slightly more negative about school experiences and felt their differences due to diabetes were more challenging. It is possible therefore that the information gathered in such studies is not fully representative of the views of all of the young people, and that individual interview methods would be a more appropriate method within this field.

Other aspects of studies that could have an impact upon the data gathered and make the information slightly less representative of the views of young people with diabetes are that certain studies involved young people who had been involved in activities such as studies and camps geared toward improving their experiences with diabetes. The majority of the studies were based within the USA, although others were based in Sweden and the United Kingdom; therefore the views and experiences of the young people within these studies are not necessarily transferable to adolescents in different countries due to the differences in relation to health care provisions and educational practices. As a result of the limitations discussed, further research into adolescents' experiences is recommended, including more diverse sampling from sources other than specialist services, and diabetic camps or specific coping skills programmes, and larger sample sizes.

Conclusion

This systematic review shows that young people's experiences with diabetes are being sought by researchers. This is a helpful development as it enables professionals working with the young people to acquire their experiential knowledge. The findings of the varied studies suggest that some aspects of their lives are challenging as a result of their diabetes, however, examples were given by participants in a variety of the studies of ways in which the people involved in their lives and their treatment supported them to achieve a greater level of normality.

Young people also made some suggestions for how things could be improved such as; for both parents and health care providers to be non-judgemental in their care, to be treated at all times as individuals and to be encouraged and supported to become independent, for peoples understanding of type 1 diabetes to increase, and for school personnel to receive more education about diabetes.

All of these suggestions warrant further investigation to develop a more comprehensive understanding of the issues, and have implications on a service provision level which should engender discussion.

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Table 1: Evaluation of the Studies using the CASP appraisal tool

Study Reference	Was there a clear statement of the aims of the research?	Is a qualitative methodology appropriate?	Was the research design appropriate to address the aims of the research?	Was the recruitment strategy appropriate to the aims of the research?	Were the data collected in a way that addressed the research issue?	Has the relationship between researcher and participants been adequately considered?	Have ethical issues been taken into consideration ?	Was the data analysis sufficiently rigorous?	Is there a clear statement of findings?	How valuable is the research?	Overall strength rating on CASP
10	Yes	Yes	Yes	Partially	Partially	No	Partially	Partially	Yes	No	Poor
11	Yes	Yes	Yes	Yes	Yes	No	Yes	Yes	Yes	Yes	Strong
12	Yes	Yes	Partially	Partially	Yes	No	Yes	Partially	Partially	Partially	Poor
13	Yes	Yes	Partially	Yes	Yes	No	Partially	Partially	Partially	Yes	Moderate/ poor
14	Yes	Yes	Partially	Yes	Yes	No	Partially	Partially	Yes	Yes	Moderate
15	Yes	Yes	Yes	Yes	Yes	No	Yes	Yes	Yes	Yes	Strong
16	Yes	Yes	No	Yes	Yes	No	Yes	Yes	Yes	Yes	Strong
17	Yes	Yes	Partially	Partially	Partially	Partially	Yes	Yes	Yes	Partially	Moderate
18	Yes	Yes	Yes	Yes	Yes	No	Yes	Partially	Partially	Yes	Moderate/ Strong
19	Yes	Yes	Yes	Partially	Partially	No	Yes	Yes	Yes	Yes	Moderate/ Strong

Table 2: A Summary of the 10 Studies included in the systematic review and the emergent themes

Study Ref	Country	Primary focus	Sampling method	Sample size	Age	Methodology	Analysis	Correspondence between review themes and original study themes
10	Sweden	To describe adolescents' experience of living with type 1 diabetes.	Convenience	8	14-18	Interview	Husserlian Phenomenology	<p>A 'To be different', 'To be treated differently' & 'To live a regular life'</p> <p>B 'To take care of oneself', 'To know one's body' & 'To live a regular life'</p> <p>C 'To be treated differently' & 'to take care of oneself'</p> <p>E 'To be treated differently'</p>
11	Sweden	Experiences of the transition towards autonomy in self-management for teenagers with type 1 diabetes.	Convenience	32	13-17	Conversational interviews	Phenomenological (Halldorsdottir, 2000)	<p>A 'Growth through confirmation of others'</p> <p>B 'Growth through individual self-reliance', 'Hovering between individual actions and support of others'</p> <p>C 'Growth through confirmation of others'</p> <p>D 'Growth through confirmation of others'</p>

12	UK	To explore the experiences of young people managing their type 1 diabetes at college or university.	Not clear	23	17-19	Semi-structured interviews - telephone	Thematic analysis	A ‘Reduced participation in social events’, ‘Aversive diabetes management strategies’ B ‘Aversive diabetes management strategies’ D ‘Transition to an adult diabetes clinic’ & ‘Balancing diabetes and further education’ E ‘Balancing diabetes and further education’
13	UK	To describe users’ experience of paediatric diabetes services.	Not clear	12	12-16	Focus group	Thematic analysis (NVivo software)	A ‘The way schools reacted to children with diabetes’ B ‘Clinic structure and process’ D ‘Experiences of communication in consultations’ E ‘The way schools reacted to children with diabetes’ & ‘Clinic structure and process’
14	USA	Pilot study to explore the meaning of the chronic illness experience for adolescents with diabetes taking on the responsibility for their own care.	Purposeful	4	15-17	interviews	Constant comparative method (Glasser & Strauss, 1967)	A ‘making it fit’ B ‘making it fit’ & ‘ready and willing’ C ‘ready and willing’ & ‘having a safety net of friends’ D ‘ready and willing’ E ‘ready and willing’

15	USA	To gain a better understanding of what it means for adolescent females to live with type 1 diabetes.	Purposive	10	16-17	Unstructured interviews	Phenomenological (Van Manens)	<p>A ‘Blending in with the adolescent culture’, ‘Standing out and being watched’ & ‘Weighing the options and making choices’</p> <p>B ‘Standing out and being watched’, ‘struggling with conflicts’</p> <p>C ‘Being tethered to the system and to diabetes’ & ‘Struggling with conflict’</p> <p>D ‘Being tethered to the system and to diabetes’</p> <p>E ‘Being tethered to the system and to</p>
16	USA	To examine diabetes care at school from the perspective of adolescents with type 1 diabetes and their parents.	Purposive	30	13-20	Semi-structured interview	Content analysis (Miles & Huberman)	<p>D ‘School staff knowledge/ training’</p> <p>E ‘School staff knowledge/ training’ & ‘Food offered/available at school’</p>

17	USA	Exploratory study of the stressors and self-care challenges faced by adolescents with type 1 diabetes	Convenience	6	13-17	Group discussions	Content analysis	A 'Nature of the condition' and 'Relationship stressors' B 'Personal', 'Nature of the condition', 'coping behaviour' & 'care management stressors' C 'Relationship stressors' & 'Personal' D 'Relationship stressors' E 'Situational stressors'
18	USA	To increase understanding of adolescent-parent diabetes related conflicts and supports from the adolescent perspective.	Convenience	24	13-15	Focus group	Focus group analysis	C 'Adolescent-parent conflict' & 'Parental support'
19	USA	To explore perceptions of how diabetes influences adolescents perceptions of quality of life and relationships.	Not clear	31	13-18	Focus groups	Qualitative analysis (5 step procedure)	A 'impact on relationships' B 'impact on relationships' & 'personal perceptions' C 'impact on relationships' D 'impact on relationships' E 'impact on school'

Bridging chapter

A greater understanding of the daily experiences of young people with diabetes in the school environment was sought by this study. Analysis of the accounts of young people's experiences can provide clinicians within the field with increased knowledge of potential barriers to them maintaining diabetes care in an environment which plays a central role in their lives; school.

Given the amount of time that young people spend within the school environment, it was somewhat surprising that research into the experiences of adolescents with diabetes had not often focused directly on that area. Over the past decade there have been a number of studies conducted worldwide which have begun to redress this deficit in understanding; however, even some of those neglected to solicit the views of young people.

Yu *et al.* (2000) investigated the academic and social experiences of children with and without insulin dependent diabetes mellitus. They used a variety of measures including parent interview to gather information. The questions posed to parents during interview focused on their child's school experiences, and peer and social experiences. Generally parents relayed that their children had positive relationships with their teachers, and the majority acceded that schools made accommodations for their child in relation to their diabetes management. However, suggestions for improvements were made by the parents involved; the most common of which was that there should be more education for school personnel regarding diabetes and elements necessary for its management. Yu *et al.* (2000) also suggested that a

potential area for future research would be to ‘ask children about their perceptions of their academic and social lives’ (p. 204).

A questionnaire study was conducted in Spain by Amillategui *et al.* (2007) with 499 parents of children aged 3-18 years with diabetes. They found that only 34% of the parents involved believed that teachers would recognise a hypoglycaemic episode (hypo), and that 97% considered it essential that teachers know at least the basic steps to manage a diabetic emergency. In the study 16% of families described having had to make changes to their children’s diabetic management regimen due to problems with the school’s co-operation.

A further survey was conducted in America by Schwartz *et al.* (2010) with 80 children and their parents, and 28 school staff. The young people indicated there were negative aspects of having diabetes at school; 70% felt they were treated differently because of their diabetes, with 11.2% having felt that they had been embarrassed by school personnel, and over 50% reporting that they had been prevented from being able to undertake diabetes management tasks. On a more positive note, 60% of the young people felt that the cafeteria provided food that fitted with their meal plans. Parents’ reported some negative experiences, however, over 50% felt that school were supportive of their child when they had to miss school for appointments, or were returning following diabetes related illness. 93.9% of school personnel in the study reported that they were comfortable working with children with diabetes. In contrast to young people’s views 65% of school personnel felt that their school were supportive of the management needs of the young people within school.

Pinelli *et al.* (2011) surveyed 220 parents and 52 school personnel of young people with diabetes in Italy. 14.3% of the parents surveyed did not feel that their child's hypoglycaemic event had been handled well in school. Poor knowledge about diabetes was felt to be a problem during school time for 22.8% of parents responding, and practical difficulties of managing diabetes in school was found to be a problem for 26.3%. With respect to school personnel's responses, 59.6% reported having had no specific training about diabetes, but 26.3% felt that their school would be able to manage diabetes related emergencies.

Overall in the studies, schools were generally reported to be supportive and make accommodations for children with diabetes. However, problems had occurred in school such that some families had had to make adjustments to their children's management regimens, and other children had been prevented from undertaking necessary management within school. Generally more knowledge for school personnel was felt to be necessary, and this was also the belief held by teachers (Pinelli, *et al.*, 2011).

A scant number of studies have been conducted utilising a qualitative approach to ascertain the views of young people in this area; however, a few have been identified. In 2003 Nabors *et al.* conducted interviews and groups involving 105 children aged 5-14 years who attended a camp in America for diabetes. The children involved in the study were generally in agreement that teachers, nurses and friends needed to improve their knowledge of diabetes. They also identified that it would be useful for teachers not to call attention to them when they needed to manage their diabetes in class. Help and support from staff and friends was seen as being

important generally and more specifically when they were feeling 'low'. A final area of difficulty described by some of the children related to after school activities which could be problematic; advising that coaches should also receive more information regarding diabetes.

A preliminary study was also undertaken with two Taiwanese adolescents (Wang *et al.*, 2010). Interviews were conducted with the two adolescents and four themes emerged. The themes related to learning: to be a master of their disease, to find ways to feel comfortable, to not be different, and to not let others worry about them. Specific comments concerning school involved understanding the importance of peers knowing about diabetes and emergency management processes, but at the same time balancing the competing demand for emotional comfort that they achieved by avoiding the attention and teasing elicited by peers questioning.

The results of the systematic review of adolescents' experiences also indicated that school experiences of adolescents with type 1 diabetes, described mainly by non-UK residents, were less than positive. Adolescents in a number of studies expressed concern about the lack of knowledge their teachers had about diabetes and how to respond to any difficulties. They also expressed dissatisfaction with school staff's lack of knowledge which had resulted in insensitivity towards them; and at times singled them out from their classmates, or had a detrimental impact upon their ability to successfully manage their diabetes within school. The majority of the reports were based upon schools within countries other than the UK, and further methodologically sound investigation of this area within other populations would also appear to be beneficial.

Impetus for the study also came as a result of what is known about the potential emotional and psychological difficulties that adolescents can face in relation to diabetes, and in order to understand the role that school can have in affecting those outcomes. Adolescence can be a particularly difficult period in the lives of young people and school, where they spend approximately one third of their waking hours on average, plays a central role in their lives during that time. Adolescence is a challenging period in the lives of young people in the school environment; Warrington & Younger (2011) studied adolescent peer group inclusion within schools. They found that it was of crucial importance for adolescents to be ‘part of the in-crowd’ and consequently young people described adopting behaviour and role identities that conformed to acceptable peer norms. They also discovered that it was not unusual for young people to consciously avoid situations that might compromise their image around peers, and that visible differences e.g. disability, marked people out as being different. Implications for the young people particularly girls of the consequences of not being part of the group in which they desired to be were emotional and psychological including feelings of loneliness and depression.

For adolescents with diabetes in addition to the typical demands of this developmental stage, they also have the added pressure of managing their condition and maintaining their health and wellbeing. Adolescence is therefore recognised as being a difficult time for successfully controlling diabetes (Thomas *et al.*, 1997). Throughout Europe, glycaemic control in young people has been identified as an issue (Bryden *et al.*, 2001; Dunger, 1992). Given that the risks of short and longer term health complications are reduced by diabetic control (National Diabetes Information Clearinghouse, 2008), it is reasonable that a major focus of diabetes

related research has been the factors influencing control (e.g. Anderson *et al.*, 2002; Farrell *et al.*, 2004).

Alongside the health impacts of problems with diabetes control, there are also psychological implications for young people. Dovey-Pearce *et al.* (2007) conducted interviews with young people aged 16-25 with diabetes to investigate the influences of diabetes on psychosocial development. They discovered that diabetes does impact on personal identity and self-concept, but that this could be mitigated by peer support. However, any on-going sense of difference that the young people felt in social interactions and with peers reinforced the impact that diabetes had on sense of self. Buchbinder *et al.* (2005) conducted a video diary and interview study with five 13-18 year olds with insulin-dependent diabetes mellitus. They found that having diabetes was associated with both negative and positive experiences with families and peers. One interesting aspect of Buchbinder *et al.*'s study was the finding that; 'participants revealed that, in stressful and beneficial ways, diabetes renders them as "other" during a time in their lives when they are intensely self-conscious and in which conformity is a survival skill, indicating the potent influence that diabetes can have on adolescents' psychosocial wellbeing.' (2005, p71.e12).

Studies have also found young people with diabetes have a greater incidence of psychiatric disorders (Northam *et al.*, 2004) with depressive, conduct and anxiety disorders being most prevalent (Kovacs *et al.*, 1997). The National Diabetes Support Team (2006) discussed the psychological issues associate with type 1 diabetes and identified that psychosocial issues are thought to be related to the increased risk of depression. A review by Delamater (2009) found that alongside psychiatric

disorders, eating disorders (highly prevalent in girls), stress, and psychosocial problems such as self-esteem difficulties are related to poor metabolic control, and have in turn been associated with worsened metabolic control and even hospitalisations.

Studies to date have gone some way to exploring these issues, however, they have generally focused on the views of the adults involved in the situation, and included young people within a wide age range. The typically questionnaire or survey based studies have involved large sample sizes and have provided some insight into diabetes management in the school environment however, understanding has been constrained by this methodology which limits their opportunity to respond. Additional research specifically relating to school experiences and eliciting the views of the young people would therefore appear justified.

The Children's Charter for diabetes (Diabetes UK, 2010a) was developed with involvement from young people, carers and professionals. The report provided examples of good practice as well as key recommendations in relation to young people with diabetes, but also recognised that gaps in services and care exist. They identified the importance of investing in services for young people with diabetes to improve their management and subsequent health and wellbeing outcomes including improving academic performance, and reducing the risk of disease-related complications. Recommendations from the report included; reducing discrimination in education, employment and public life, giving young people a say in the services they receive, and ensuring that all young people have access to high quality

education, information, emotional and psychological support to aid self-management of the condition (Diabetes UK, 2010a).

A recent report by Diabetes UK (2007) also recognised the benefits of engaging young people in designing diabetes services including; empowering them, and ensuring that services are tailored to their needs based upon their experiences.

Therefore, determining young people's perceptions about type 1 diabetes and its management through this type of study can help to identify potential implications for practice which can help young people to overcome the difficulties they have experienced. In addition the study outcomes can be used to inform those people who are involved in young people's day to day lives; such as teachers, about the issues that young people are facing whilst trying to manage their diabetes.

Aims

The purpose of the study was to learn more about the experiences of adolescents with type 1 diabetes and more specifically to achieve further comprehensive understanding of their daily experiences within the school environment. It was anticipated that gaining their perspectives on their positive and negative experiences of managing diabetes in school would enable professionals working with them to achieve insight into areas affecting successful diabetic control. Existing research has recognised the difficulties that adolescents have in managing their diabetes (Bryden *et al.*, 2001; Tfayli & Arlanian, 2007), and the profound impact that diabetes can have on emotional or psychological wellbeing (Diabetes UK, 2010b). A large amount of research has focused on the issues of glycaemic control, influential family factors, and latterly peer relationships for young people with diabetes. One area which appears to have received less attention is that of the impact of school experiences on diabetic control. This study intended to provide a degree of insight into the experiences of teenagers attending school whilst managing type 1 diabetes. It aimed to discover who or what had impacted upon their diabetes management day to day within school. And further to collate and disseminate the findings in such a way as to provide the opportunity for growth and development within schools to further support the complex needs of this group of teenagers.

Method section

Ethics process and permissions

The project was initially submitted for consideration to the NHS National Research Ethics Service (NRES) in December 2011. At that stage it was rejected and a recommendation was made for it to be resubmitted. Amendments were made to the project in line with the recommendations and it was considered and approved by the local NRES committee in February 2012 following minor amendments (Appendix 1). Approval was also given for the amendment; to invite participants to provide feedback on the analysis (Appendix 1). The project also received approval for the Research and Development Committee of the local NHS trust (Appendix 2). Permission for the project to take place was given by the consultant paediatrician for the service. The diabetes specialist nurse for the service was supportive of the project taking place, and agreed to assist with the process of identifying potential participants based upon eligibility criteria.

Eligibility

Given the focus of the study, young people who were in school and living the day to day experiences of managing their type 1 diabetes within that environment were suitable for recruitment. Young people were eligible to participate if they were aged between 13 and 16 years inclusive, had had a diagnosis of type 1 diabetes for more than 6 months (to allow them a period of time to adjust to their diagnosis and to establish a management regimen), and were attending school.

Young people were not eligible to participate if they had a coexisting chronic health condition. The reason for that was the possibility that their experiences may have been different to that of young people with type 1 diabetes on its own, e.g. their management regimes might have been even more complex.

Recruitment

Recruitment occurred within the local NHS trust. Young people were purposively recruited through the local paediatric diabetes service. The chief investigator (SY) liaised with the specialist diabetic nurse to discuss eligibility criteria. The diabetes nurse then identified potentially suitable participants, and provided the chief investigator with the names and postal contact details of potential participants. Participants had no prior relationship with the chief investigator who had no knowledge of their medical history or access to their medical records.

A total of 23 young people met the eligibility criteria within the region and were all of the potential participants. Letters of invitation for both the young person (Appendix 3) and their parent/guardian (Appendix 4) were sent out along with an opt-in slip and a more comprehensive information leaflet (Appendix 5) to all 23 potential participants. The invitation letter and information leaflet provided information regarding the purpose of the research. It explained that the project would provide the young people with an opportunity to discuss their experiences with someone independent to both school and the diabetes service; to voice their perspectives and provide information that could help to inform future practice. Contact information for the chief investigator was provided so that potential participants could make further enquires about the project.

Each of the young people contacted were asked to return the opt-in (Appendix 6) complete with details of the best method of contact if they were interested in participating. Once the opt-in slip was received by the chief investigator, the young person and their family was contacted by telephone to confirm their interest in participating. All of the young people who returned opt-in slips agreed to participate in the study at that stage and the interview was then arranged at a time suitable for the young person. A total of seven young people (1/3 of the overall eligible population) participated in the study.

Data collection

The study employed an Interpretative Phenomenological Analysis (IPA). The IPA approach was chosen as it allowed for a detailed analysis of the perceptions of the participants about their experiences of dealing with diabetes in the school environment. The IPA approach is committed to examining how people make sense of major life experiences, and the aim is to examine in detail what that experience is like for the individual and what sense they have made of it. It also aims to draw together a homogenous sample in order to examine the similarities and differences that emerge given a relative shared experience (Smith, Flowers & Larkin, 2009; Smith, 2011). For these reasons the IPA approach fit well with the aims of this study which were to better understand the experiences of young people aged 13-16 with type 1 diabetes in the school environment.

Data for this analysis were gathered by means of individual semi-structured interviews with the young people, which are seen to be the most effective way of gathering information for IPA studies (Smith & Osborn, 2008). This method of data

collection was chosen as it allowed flexibility for the individual participants to express their experiences in their own terms and give detailed accounts whilst still working with a structure to enable the aims of the study to be met.

Interviews were arranged with families outside of school hours to minimise disruption to education. The interviews were conducted in an NHS setting outside of the usual clinic room participants normally attended for diabetes check-ups so that there was a differentiation between the study and care provision. Participants were given £10 to cover travel expenses incurred in participation; however they were not informed of this prior to agreeing to participate so as to remove the potential of a financial incentive.

Consent

On attending for their interview participants were asked if they agreed to participate in the project, and were given an assent form to read and sign (Appendix 7). As the participants were aged 16 or younger their parent/guardian was also asked to read and complete a consent form (Appendix 8) before individual interviews with the young people commenced. Interview sessions were conducted by the chief investigator and were audio recorded with the consent of the young people.

Confidentiality

Given that the participants were drawn from a relatively small cohort, there was a possibility that information given by participants in interviews may have included identifying details. It was necessary to address this with the young people prior to their giving assent. Participants were made aware that their direct quotes could be

used in the final written report of the study; but that any quotes would be made anonymous and identifiable information would be removed or altered and names changed to protect the identity of participants.

To maintain confidentiality, the interviews were introduced by the chief investigator on the audio recording by the participant number only. The interview proceeded to follow a semi-structured format (Appendix 9) which involved questions in three main areas: peer responses to the young people with diabetes, school staff members' responses, and practical aspects of managing diabetes in school. The interviews varied in duration of between forty minutes and one hour. The young people were made aware that they could withdraw their participation at any point within the process.

Until such a time as the recording was transcribed, it was stored in a separate locked cabinet to information linking the young person to their participant number. The locked cabinet was situated within a secure office in the local NHS trust CAMHS service. Only the chief investigator had access to the information linking participants' names and participant numbers.

The audio recordings of the interviews were transcribed verbatim by the chief investigator. All of the interview transcripts included the interviewer's questions as well as participant responses. IPA transcription is at the semantic level and therefore all of the words, as well as pauses, laughs and other significant features of the interviews were included in the transcripts for consideration during analysis. Identifiable information was removed during the transcription process, and the written document was labelled with the participant code number and securely stored.

Data Analysis

Data analysis followed IPA methodology guidelines (Smith, Flowers and Larkin, 2009). Transcripts of the semi structured interviews were written up in such a way that space was allocated for the investigator to make analytic comments at both sides of the text.

The first transcript was read through a number of times. On the first pass any areas of significant interest were identified and annotations were made on the transcript, including brief summarising comments, paraphrasing's of the young people's descriptions, initial connections between themes within the text, and any preliminary interpretations. Rereading of the initial transcript allowed the investigator to begin to identify emerging themes. Those themes which began to emerge were recorded in an initial list in the order in which they became apparent when the transcript was being analysed (Appendix 10).

Further to that process a second, more analytical list was created to begin to order the emerging themes and to try to make more sense of any possible connections. A final table was then developed, and was used to capture the participant's concerns on the topic. Portions of the transcript in which instances of each theme were illustrated were recorded at this stage.

Having completed analysis of the first transcript in this manner, the chief investigator used the tables as a basis upon which to build and incorporate the information gathered from the remaining interviews. The existing themes from the analysis of the first transcript were used to orient the analysis of all subsequent transcripts. Any new and different themes emerging from the later transcripts were identified and included

in the theme table, as were any portions of subsequent transcripts which provided additional support to the existing themes.

Once all of the transcripts had been analysed in that manner, a final table of superordinate themes was constructed incorporating themes and quotes from all of the young people's interview transcripts. The chief investigator collaborated with her clinical supervisor throughout the analysis process; discussing and reflecting upon the transcript content, the coding process and the emerging themes (example transcript see Appendix 11).

This final analysis stage provided the basis for a narrative account of the interview outcomes and analysis to reflect the meanings from the participants' experiences, distinguishing investigator interpretation from participants' statements. In order to maintain anonymity the names of the participants were changed.

Quality Assurance

In order to assure the quality of the study a number of steps were undertaken (see Table 1).

Feedback on the outcomes of the study was sought from the Diabetes Specialist Nurse and a secondary school teacher to establish their perspectives on the themes that emerged from the study and the conclusions drawn, and these are included in the results section.

As part of a quality checking process for the study the seven participants were re-contacted following the study to invite them (see Appendix 14) to participate in a

discussion to elicit their views on the chief investigators findings and the themes that had emerged during the analysis. However, none of the participants chose to take part the proposed telephone feedback discussion.

Table 1. Methodological rigour steps undertaken to ensure study quality.

Rigour Method Activity	Evidence
Creation of the interview schedule: Discussion within clinical supervision and utilising IPA methodology set out in Smith <i>et al.</i> , 2009.	Chapter 4, Smith <i>et al.</i> , 2009. Interview Schedule (Appendix 9)
Reflective supervision including discussion of the interview process, transcriptions, coding, theme establishment and analysis	Sample of supervision records (Appendix 11).
Evaluation of study using CASP evaluation tool	Table (Appendix 12).
Evaluation of IPA research using guide provided by Smith (2011).	Table (Appendix 13)
Reflecting on the outcomes of the study with professionals including Diabetes nurse and school teacher.	Discussion in result section
Review outcomes with participants to elicit views on the conclusions draw. Invited participants to participate in telephone interviews to give feedback on the study outcomes.	Invitation letter (Appendix 14).

Experiences of Type 1 Diabetes in School; An Adolescent Perspective.

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Abstract

Aims: Type 1 diabetes is a condition affecting thousands of young people throughout the UK. Existing research has recognised the difficulties that adolescents have in managing their diabetes, and a large body of research has focused on glycaemic control, and influential factors. This study attempted to provide insight into the experiences of teenagers attending school whilst managing type 1 diabetes.

Method: Participants were recruited from the local paediatric diabetes service. 7 young people aged 13-16 with a diagnosis of type 1 diabetes participated in semi-structured interviews which focused on their experiences of type 1 diabetes within the school environment. Interpretative Phenomenological Analysis (IPA) of the interview transcripts was undertaken.

Results: Four major themes emerged from the analysis: Support, Knowledge and Understanding, Standing out, and Adjusting and Accepting.

Discussion: Many of the young people had encountered negative experiences in relation to having type 1 diabetes within the school environment. However, they also described elements of helpful practice and had suggestions for improvements that could be made within school to facilitate a more positive experience.

Introduction

Adolescence can be a particularly difficult period for young people and school plays a central role in their lives during that time. Adolescents encounter a number of developmental challenges including: striving for increased independence, developing relationships, and coping with academic demands [1]. In addition to this adolescents with type 1 diabetes have to manage their condition, which can be particularly difficult during that period [2, 3].

Given the amount of time that adolescents spend within the school environment, it is somewhat surprising that more research relating to adolescents with diabetes has not focused on this area. Over the past decade studies have been conducted worldwide which have begun developing understanding; however, often these have neglected to solicit young people's views [e.g. 4, 5].

Parents were often doubtful about teachers knowledge of diabetes [4, 5] and in one study [6] made suggestions about how the academic and social experience of their children could be improved, the most common being that there should be more education for school personnel regarding diabetes and elements necessary for its management.

One study involving the views of children [7] found that they generally agreed that teachers, nurses and friends needed to improve their knowledge of diabetes, and identified that it would be useful for teachers not to call attention to them when they needed to manage their diabetes in class.

Studies have begun to explore the issues of diabetes within school; however, they have generally focused on the views of the adults involved. Questionnaire or survey based studies [4, 5, 7] have provided some insight into diabetes management in the school environment. However, understanding has been constrained by this methodology which limits participants' opportunities to elaborate.

Additional research specifically relating to school experiences and eliciting the views of adolescents themselves is therefore required. It is important to include the views of the people involved when undertaking health care research as it provides information from them as experts of their own experiences [8].

The purpose of the present study was therefore to learn more about the daily experiences of adolescents in the school environment; a place in which they spend a significant proportion of their time. Analysis of the accounts of young people was expected to provide health professionals with an increased knowledge of potential barriers to maintaining diabetic care in the school environment. It was anticipated that health professionals working in the field of diabetes could use this understanding to tailor information and guidance to school personnel regarding the needs of pupils with type 1 diabetes; but also to enable them to collaborate with the young people to implement adaptive strategies to deal with management difficulties associated with school.

Method

The study was approved by the National Research Ethics Service and local NHS Research and Development Committee.

Participants, eligibility and recruitment

Participants were purposively recruited through the local paediatric diabetes service, and were eligible to participate if they were between 13 and 16 years of age, had been diagnosed with type 1 diabetes for at least 6 months, and were attending school. Young people were not eligible to participate if they had a coexisting chronic health condition. The reason for that was the possibility that their experiences may have been different to that of young people with type 1 diabetes on its own.

Participants had no prior relationship with the chief investigator (SY) who had no knowledge of their medical history or access to their medical records.

23 young people were identified by the diabetes specialist nurse as being the total eligible population. Letters of invitation, an opt-in slip and a comprehensive information leaflet were sent out. Upon return of the opt-in slip the family was contacted by telephone to confirm interest and arrange the interview outside of school time. Seven young people (1/3 of the total population) agreed to participate and were interviewed.

Data collection

Data were gathered by means of individual semi-structured interview, which are seen to be the most effective way of gathering information for IPA studies [9]. This

method of data collection was chosen as it allowed flexibility for the individual participants to give detailed personal accounts of their experiences, whilst providing structure to enable the study aims to be met. Interviews were conducted by the first author (SY) in NHS premises outside of the diabetes clinic setting, to differentiate between the study and normal care provision, and the recordings were then transcribed verbatim.

Participants gave assent and their parent/guardian gave consent to participate and for the interview to be audio recorded. To maintain confidentiality participant numbers were used on study materials. Participants were aware that direct quotes could be used in the final written report with identifiable information removed. Participants' names were changed to protect their identity.

Analysis

An IPA approach was chosen for this study given its focus on examining in depth how people make sense of major life experiences and what that experience had been like for the individual [10, 11]. For these reasons the IPA approach fitted well with the aims of this study; to better understand the experiences of adolescents with type 1 diabetes in the school environment.

Analysis of the transcripts was conducted by the first author (SY) following recommended analysis steps [10] and initial themes and interpretations were noted. The initial transcript was read, emerging themes were listed and then analysed to begin to order them and make sense of possible connections. Portions of the transcript in which instances of each theme were illustrated were then recorded.

Themes from the first transcript were used to orient the analysis of subsequent transcripts. New themes emerging from later transcripts were included in the theme table along with sections of transcript adding support. Following the emergence of new themes, earlier transcripts were re-read to identify supportive material. A final table of superordinate themes was then constructed incorporating themes and quotes from all transcripts. It provided the basis for a narrative account of the analysis; to reflect the meanings from the participants' experiences and the investigators interpretations. Throughout the analysis process the chief investigator participated in regular reflective supervision sessions and discussions with her clinical supervisor to assure rigor in the methodology. Methodology and validity was also evaluated using qualitative methodology analysis tools.

Participants were approached again at the conclusion of the study to provide feedback upon the outcomes, however none chose to participate. Views on the study were also sought from the diabetes specialist nurse and a secondary school teacher as part of a quality control check.

Results

Seven adolescents took part in the study; 1 male and 6 female, and their characteristics are shown in Table 1. Analysis of the interview transcripts led to the emergence of four major themes; ‘Support’, ‘Knowledge and Understanding’, ‘Standing out’ and ‘Adjusting and Accepting’.

1. Support

Having support in both practical (‘Practical support’) and emotional (‘Supportive people’) terms was important to participants.

1.1. Supportive people

It was important for participant to feel they had the support of people within the school environment, and successful diabetes management within school could be facilitated or hampered by the actions of others.

To know there was an approachable and available member of staff was valued.

Andrew reported; *“I always find it helpful to have someone to go to, like my guidance teacher always seemed to be available to go and talk to.”* This sentiment was mirrored by Beth who said, *“... if I ever need to talk about it or let someone know that something’s happened I can go and talk to them.”*

Friends could also be counted on to provide support, and doing so during diabetic incidents gave adolescents confidence to become increasingly independent from their families and immerse themselves in adolescent culture.

Practical support and backup from friends was appreciated by Donna who recalled; *“one of ma close friends... she carries sweeties in her bag for me ...and I think it’s like so sweet, cause if I feel low she’s like ‘oh, I’ve got Haribos in ma bag for you’”,*

and Erica who described, *'he was always there for me if I was getting a hypo...if I'd go call on him he's like give me two seconds, and he'd go to the cupboard and put some stuff in his pocket in case I pass out or something'*.

Gail explained; *"I've got this friend...she's like always been in my class, she always knows what to do she's supported me with a ton of hypos and everything she's em got like my bm kit out of my bag and helped me prick my finger helped me get dextrose and food."*

Andrew's friends sought knowledge to enable them to support him on his first school trip abroad; *"we're going away to Holland with the school ...there's like a room of four, and they [friends] were saying er if something happens what do I do? ... I don't think they would particularly know what to do... but I know that they would have the sense to go and get someone."*

Friends support in the face of people's ignorance was particularly helpful for Erica in relation to school staff *"I had this one teacher, um and was having a hypo but I didn't have anything sugary on me, and the teacher was like 'oh just leave her she'll be fine, it'll wear off in a minute', but... my sisters friends... were like 'no, if we leave it then she'll be in hospital'. And she [teacher] was like 'no, it'll wear off, it'll be fine!' and she [friend] went got some chocolate and just walked into the class ... and I was just eating this chocolate bar, and they were there rubbing my back saying 'you ok?' ...So they were really supportive."* And hurtful comments from peers *"this one person, he called me a druggy, 'cause I have to take insulin and whatnot, and that really hurt me. I went to the teachers and then urm they said they'll speak to him, then ... 'cause they didn't speak to him that day...he [friend] asked me what's*

wrong, and I told him and he went and he had a right go at him, and I was like 'yay!'. ”

1.2. Practical supports

The practical support put in place by schools had been fundamental in allowing participants to manage their diabetes successfully within school. One adaptation was permission to leave class early prior to lunch to undertake injections. Of those who needed that concession there were mixed views on how helpful it was depending upon how it was handled, and if they remained integrated with their peers.

Freya initially needed to go early as she required help with her injection, however it was a negative experience; *“they used to let me out of class 15 minutes early so that I could like get ma lunch and stuff before everybody else and that, but... it meant like you didn’t have your friends to go to lunch with and stuff.”*

For others it was more positive; as Andrew described, *“I get let out five minutes before everyone else at lunch...so I can go and get lunch, it’s because ... if I get in late, there wouldn’t be enough food...so I would always get first and then I can get what I want to eat, and then by the time I’ve done my checks, everyone else is down and eating...”*. Being allowed a friend to accompany her made it less isolating for Beth, *“I get out 10 minutes early at lunch to go and do it...and I get to take someone with me outta that class every time.”*

Participants all had access to a medical type facility or nurse within school time, however, the facility represented different things to each. Andrew utilised the nurse initially *“I would go down to the nurse and I would do my blood sugar and that with the nurse”*, but over time the role became precautionary: *“[I] kept a tester with the*

nurse so if I ever like...like ran out of strips, my tester broke or something, I could always go down there and it was always reassuring to have a backup.”

Other participants also felt secure in the knowledge that it was there if they needed, including Clare who said, *“when I need to do my injections I can just go to there to the medical room and stuff, and they took some of my like hypo stuff just to make sure that if I was ever hypo they definitely had something there to make sure I’d be fine...I can just go to the medical room and do it whenever I want, but I never use it”.*

However for Gail it was an ineffective resource as she explained: *“There is a school nurse, but she’s like based elsewhere, so she’s like never at our school... it’s really bad...I feel um like less safe if you understand, yeah, like if I go hypo I know it’ll just be like I’ll have to take it into my own hands basically.”*

It was important for the young people to have support available if needed and lacking it made them feel apprehensive and alone. However, it was often more a safety net as their responsibility over diabetes management increased, and it became a source of frustration when forced upon them unnecessarily.

2. Knowledge and Understanding

People knowing and understanding about diabetes made a significant difference to the ability of participants to successfully assimilate diabetes into their school lives. Some of the biggest hurdles to success came as a result of the actions of others who lacked knowledge.

Andrew described *“it was embarrassing sometimes like...if we had a cover teacher, and the teacher didn’t know, and like if I said I wanted to go to the toilet and they wouldn’t let me, then I’d have to say I’m a diabetic can I please go to the toilet... it was quite embarrassing”*, Beth had a similar view *“if you have cover teachers or that it’s quite awkward ‘cause like I get up and leave, and they’re like ‘where are you going?’ and then you have to say in front of the whole class ‘I’ve got to go and do my injection’.”*

Teachers’ inadequate knowledge had led to situations that were frustrating because of unnecessary fuss. Clare revealed: *“I don’t tell them [teachers] if I don’t need to... ‘cause then they just get worried for stupid stuff, and there’s no point...like in my old school, I’d be hypo ...like I can manage it really fine and stuff I just eat, but they’d all be like fussing over me...like ‘oh, sit down, have this’ and there was a lot of hassle and stuff, and it doesn’t need hassle, just eat and it’s fine”* and Donna *“you got some teachers who tell you to go down see the nurse cause they think you’re gonna faint...they just...it’s like ‘oh you’re diabetic you’ve got to go down ...down to see the nurse’ ...I don’t have to go down see the nurse I can manage it myself”*, and finally Erica who shared: *“it’s kind of annoying ‘cause I say I feel sick, ...if I feel like ill... they’re like ‘oh, what’s your numbers? Is it something to do with your diabetes’ it’s like... being ill isn’t always about diabetes.”*

In some cases, deficient knowledge led to actions which could jeopardise their health and reduced their sense of security within school. Erica recalled, *“when you’re having a hyper like really high they’ll be like ‘do you need some food?’ it’s like ‘no!’”* Beth experienced similar; *“one time I got sent down [medical room] because my level was like 25 of something. Um, and the first aider was there...and to get my*

level down I can exercise or eat carbohydrates. So...well she said 'do you need anything?' And I said 'well if you've got any rich teas or digestive biscuits?' Um, and she came back with shortbread...but shortbreads got loads and loads of sugar in it".

There was concern that emergencies could arise and staff would have insufficient knowledge to help e.g. Freya: *" they've got medical staff at our school, and like... if I go down there and I test my blood...say my blood sugar was like 2.7 or somin' and they're like 'oh what do we do now?'. But in that time, I coulda' been like on the floor like with them not knowing what to do",* and Beth; *"I don't really do anything to make it go down that low, but if I ever did then I would be quite worried, because no-one would really know what to do. And I couldn't do anything."*

For participants having ineffectual resources was unhelpful and highlighted their need for self-reliance; added pressure within an environment in which they should expect to be nurtured and supported. There was an overwhelming consensus that staff within school should know more about type 1 diabetes and its management, the reasons behind the adolescents wanting this varied however, it was generally in order to help them to feel both safer and less conspicuous at school.

Peers' lack of knowledge had also been difficult for participants; however, initial problems generally became less of an issue once awareness increased. Andrew recalled, *"I suppose at the start it got on my nerves, like every single person like if they noticed you would ask you ...that would get annoying, but that settled down."*, Donna described, *"I think some of them seen me eating in class, and you do kinda hear the little whispers sometimes 'why's she eating in class' and things like*

that...when I first went into high school it really bothered me ...But as people are getting to know you are hearing less and less of it... ”. For Erica explaining diabetes to peers had caused problems: “But like the worst way that people have reacted is like when I tell them and then ‘cause... um I’m told it’s a disease and it’s not at the same time....so that’s what I told people, and they’d back away, and I was like ‘it’s not contagious, you can’t catch it’ and they were like ‘you’ve just got it you don’t know that’”, and for Clare previous negative experiences made her disinclined to tell people: “we were watching this thing about fat people having like all McDonalds and having like type 2 diabetes ...and like a couple of people asked me ‘oh, isn’t that you, you’ve got diabetes and stuff?’ and they’d been thinking type 2 with a really bad diet and people’d been thinking I’ve got a really bad diet and so I tend not to tell people because of that reason.”

Peers’ reactions were not always negative, and in fact many sought additional knowledge. This had been Andrew’s experience: “*other classmates just as they noticed they would ask me. But, they didn’t like make a huge fuss about it they just asked me*”, and Beth’s, “*well when I first got it, two of ma closest friends, they came up and they were quite interested in it like ‘oh what’s this? What’s this?’ like, they wanted to know what it was and what to do.*”

3. Standing out

Young people were keen not to stand out from others. Unfortunately diabetes is quite an obtrusive condition requiring injections and other management strategies.

It was important for participants to minimise the attention on themselves. Beth used a strategy suggested by the school to achieve greater anonymity: “*I sit at the back of*

most classes because I was told to sit at the back for like if I was to do a test or that, just so it was better for me...” as did Donna, *“they’ve either just said maybe go step out so that nobody kinda sees you eating or... things like that”*. Clare found that adjusting her regimen with medical support helped: *“that’s why a lot of people don’t know I’m diabetic, just because I’m just so like free about it, so I’ve got a pretty good regime as well which means I can be free”* as did Gail; *“they were gonna put me on a four a day [injections] and then I was like no I can’t do it at school it’s too it would single me out even more...so they like put me on two”*.

Erica reported strategies could still feel awkward; *“like with exams... they’ve [teachers] said that ‘if you get a hypo then just put your hand up and then walk out’, and then one of them will follow me. But...everyone at my school has a thing about people staring at them like even if we’re going to the toilet, ‘cause ...I don’t think we’re supposed to go to the toilet in exams, but we’re allowed, so when you’re walking out everyone just stops their work and stares at you ... it’s the way it makes you feel like you’ve just done something wrong.”*

Some strategies helped adolescents avoid attention; however, they were not prudent medically. Freya described, *“I used to do that in first and second year if ma blood sugar was low, I used to like try and survive...if it was like half way through the lesson I’d try and just survive the whole lesson so I don’t have to say ‘oh my blood sugars’ low’”*, and Clare reported, *“when I did my maths exam I was hypo ...the maths teacher brought me up in front of the whole class to give me my test and stuff, and then I couldn’t say in front of the entire class that I was hypo so I just did the test anyway... like I knew I was hypo and I was really dizzy, and I couldn’t make sense of any of it”*.

Gail recounted two experiences when she had remained silent so as to blend in; *“I had a hypo in one of my exams ... about half way through the exam I realised I was ...I started shaking and everything, and I dealt with it in the worst way possible, I just waited I sat and waited until the exam ended I was like too scared to like speak to the invigilator”* and *“like I’ll sit there [when hypo] like I’ll just like stare off with my hands shaking and everything and then but sometimes like I don’t speak, I’ll just like wait until the period is finished...[why?] Like it’s really strange I feel like I’m interrupting the lesson or something.”*

4. Adjusting and Accepting

Participants were grateful when peers let them undertake diabetes management without a fuss. Andrew said, *“people like notice if you’re like eating chocolate before your sport, or they notice if you taking injections at lunch time ‘cause I just take it at the canteen just sitting at the table ... no-one really makes a fuss about it. No one treats me any differently because of it.”* Beth’s friends let her do what she needed: *“it’s been ok because we go and get food and then we sit down somewhere so I can do my jab and stuff, and then we’ll sit and eat...some of them [friends] don’t really ask questions, but they know I need to do it ...they don’t involve their selves.”*

Clare recalled, *“I think everybody was pretty good. Like, even all the schools I’ve been to and high schools and that, I don’t remember anyone really being like not ok with me going and check my bloods and stuff. I don’t remember anybody being nasty or nothing about it.”* And for Freya: *“[friends] know more about it now, and understand more than what they did before, so it’s like easier now to get on with more people... they’re like totally fine now with it all... ‘cause like we’re with each other 24/7 they’re like getting to grips with everything.”*

Teachers also helped participants to manage their diabetes by supporting them to manage it without fuss. Andrew felt pleased when his sports teacher enabled him to participate: *“one day last week the teacher that has my chocolate was off and my chocolate was all locked in a cupboard so one of the PE staff actually went into his lunchbox and gave me some of the chocolate out of his”*. Beth was pleased to be consulted about her needs on a recent trip *“the teacher that took us asked me what time would suit me for lunch, whereabouts like what time and things, so, that was quite good...well kinda they fitted it around me.”*

For Donna teachers who let her manage a ‘low’ in class were seen as helpful e.g. *“I took out a big bag of Doritos and I think it was a big apple juice... and I ate it and she [teacher] was fine...and I thought...that’s what every teacher should be like...they should just let you kind of get on with it...”* For others being allowed to leave class was better e.g. Erica who said, *“the teachers are like cool ...if I go up to them and say ‘I need to do my numbers’ they’re like ‘ok’ so I get my number and then I’ll just walk out”* and Freya who reported *“if I feel like my blood sugar is low...I just say to them that ‘oh, I need to go check ma blood sugar’ and they just let me.”* Management of diabetes is therefore unique to the individual, and the participants appreciated the flexibility to manage their condition as they wished.

Feedback from the diabetes specialist nurse supported the themes that had emerged from the analysis. She reported that a number of young people had encountered some of the difficulties described e.g. difficulties with relief and teachers covering others classes who don't know pupils, and in terms of standing out there were issues around the risks that young people put themselves at so as not to be different

She reported finding some of the insights from the study helpful and that as a result she will now be revisiting children within their schools to try and discuss on going issues around their diabetes in schools and to attempt to further “*provide individual diabetes care according to the needs of child.*”

Feedback from a senior school teacher was that she had believed that she knew about diabetes, but that hearing the study outcomes and the experiences of the young people really raised her awareness of some of the issues for them within school. She also reported that reading the study had increased her interest in attending specific training in the future.

Discussion

Having reliable, knowledgeable support within school as and when it was needed was helpful for participants. This has previously been indicated as giving young people a sense of security in managing diabetes [14]. However, as found in this study, being forced into accepting unnecessary help was frustrating for adolescents. Support from people in school who had little knowledge was counterproductive and left the adolescents feeling insecure, something which has also been found by previous studies [4, 5].

Peer support had made it easier for participants to adapt to their diagnosis and integrate diabetes into their lives. Being aware that friends knew what to do if they became unwell was comforting to participants, even if they felt secure in their own abilities. The knowledge and understanding of peers was appreciated by participants; reducing their sense of being different, and enabling them to feel secure within their peer group, both of vital importance given their developmental stage.

Unlike young people in one study [12], most of the participants in this study had not been prevented from undertaking diabetes management, and some schools had provided practical adaptations to enable management. Participants in this study described the types of practical support that had been made available to them and discussed their utility. Strategies were viewed as being helpful when they were mindful of peer relationships and minimised attention. Having access to medical support engendered participants' confidence and was therefore endorsed as a helpful facility, however this was only the case in situations where staff were knowledgeable.

At times despite their best efforts to minimise the attention on them within school, they were unable to remain unnoticed, and it was awkward and embarrassing for them when questioned about their need to leave class for diabetes management by unknowledgeable teachers. Given the apparent abhorrent nature of standing out, it was understandable that these participants, like those in other studies [7, 12] were keen for teachers not to draw unnecessary attention to them or behave in ways that made them stand out [13]. Striving to avoid attention had also led to some participants behaving in ways that were not conducive to their health, suggesting that they were willing to jeopardise their health rather than stand out from peers within school.

Experiencing the ignorance and prejudices of others had been difficult for a number of participants and would suggest that increasing people's knowledge of the condition is essential. This had been a significant theme emerging from families in a number of research studies [4, 6, 14]. Teachers [5, 12] also felt they had insufficient knowledge about diabetes, and were concerned they were underprepared to manage diabetes incidents [12]. Many studies had suggested teachers improve their knowledge [4, 7] or receive more training [5, 6, 14] about type 1 diabetes.

In this study it was discovered that during hypoglycaemic episodes when they were physically unwell and perhaps unable to gain control by themselves, acknowledging that staff would be incapable of providing the help they needed was frightening for participants. It was therefore a particularly strong recommendation by participants in the present study that school staff should be given more knowledge of diabetes because without it they felt both isolated and embarrassed, but also insecure.

This study was able to gather in depth information from adolescents about their experiences of having type 1 diabetes and the sense they have made of them within the school environment. Unlike the majority of other research in the area, this study gave young people the opportunity to tell their story. As a result detail emerged in relation to the practical and emotional difficulties related to managing the condition within school. This study has provided a unique perspective on the potential social, emotional and psychological impact on the young people of practical strategies, lack of knowledge and relationships within school.

This study was undertaken using small sample of predominantly white female adolescents. Findings are based upon the experiences and perceptions of the adolescents involved and might therefore not be reflective of the views of other people within the school environment. Further research involving a larger more diverse sample would appear justified and perhaps including staff experiences would provide a balance to the overall picture. Despite these limitations, findings indicated that staff should be given more specific knowledge of type 1 diabetes and its management, strategies to manage diabetes and any related emergencies discreetly should be proactively established and shared within school and schools should be aware that as they mature young people with diabetes can become more capable of managing their diabetes, but that support facilities should remain available if they need to use them.

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Conflicts of interest

The authors declare that they have no conflict of interest.

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Table 1. Study Participant Characteristics

Participant	Age	Age at diagnosis	Duration since diagnosis (years)
1	14	13	1
2	14	12	2
3	14	4	10
4	15	6	9
5	16	12	4
6	16	8	8
7	16	3	13

Additional Results

The total population of 23 eligible young people were invited to participate in the research and their characteristics are detailed in Table 2, duration since diagnosis was not possible to establish for the entire population.

Table 2. Total eligible population characteristics.

Characteristic	Total N=23	Number of young people
Gender	Male	7
	Female	16
Age	13	0
	14	10
	15	5
	16	8

A total of seven (one male and six female) white British young people aged 14-16 participated in the study which was 1/3 of the total eligible population and their details are described in Table 3.

Table 3. Characteristics of the young people participating in the study.

Participant	Age	Age at diagnosis	Duration since diagnosis (years)
1	14	13	1
2	14	12	2
3	14	4	10
4	15	6	9

5	16	12	4
6	16	8	8
7	16	3	13

Interpretative Phenomenological Analysis of the interview transcripts led to the emergence of four major themes plus 1 additional theme as described in Table 4 below. Additional sub-themes (highlighted) and themes which had less supporting evidence or less meaning for the young people and were therefore not included within the journal article are reported below along with a brief description of existing results. Participants' names were changed to protect their identities.

Table 4. Themes emerging through Interpretative Phenomenological Analysis of the Interviews.

	Main theme	Sub-theme	Participants discussing theme
1	Support	Supportive people	Andrew, Beth, Clare, Donna, Erica, Freya, Gail
		Practical supports	
		(Paving the way)	
2	Knowledge and Understanding	Knowledge is important	Andrew, Beth, Clare, Donna, Erica, Freya, Gail
		(School staff Knowledge)	

		(Others who understand)	
3	Standing out	Standing out	Andrew, Beth, Clare, Erica, Freya, Gail
4	Adjusting and accepting	Getting on with it.	Andrew, Beth, Clare, Donna, Erica, Freya, Gail
		(Becoming responsible for diabetes)	
		(Becoming more comfortable)	
(5)	Over and over	Over and over	Andrew, Beth, Donna, Erica, Gail

1. Support

Within the theme of support it was important for participants to have both practical and emotional support.

1.1. Supportive people

Participants found it helpful to have the support of other people within the school environment, and success in managing diabetes within school could be facilitated or hampered by the actions of others including staff and peers.

1.2. Practical supports

The practical support of school personnel and of peers was important to the participants and enabled them to manage their diabetes within the school environment. This type of support was found to be most beneficial when it enabled continued integration with peers in school.

1.3. Paving the way

A third and additional subtheme within the theme of support was identified as paving the way.

It was hard for participants initially to go through the process of letting members of staff know about having diabetes, and for many having somebody to support them to do so or to pave the way in that process was described as being helpful. The role was often undertaken by the guidance teacher including for Beth, for Freya who recalled *“the guidance teacher she was just the one who...I think it was in like an email, she just sent to most people...like all ma teachers that I had. So she was like really helpful”* and for Donna who believed it made things much easier *“I had a pretty good er guidance teacher at that time and he was like really supportive and things like that, so he kinda sent like...erm... before I had actually went into some of ma classes and things he sent emails round saying right she’s a diabetic...things like that. So it kinda really helped that as well ‘cause they’d actually seemed to take more action, instead of like us having to say to them yes I’m a diabetic they all kinda already knew ...right so it was easier.”*

For Andrew it was his mother who took on the role within school *“mum gave everyone a letter before I started...right...to save just me having to tell everyone, or forgetting to tell people”*, and this was also the case for Clare to enable her to go on school trips *“So for school trips and stuff... my mum always has to have a meeting with one of the teachers making sure they know what they need to do and any special dietary requirements.”* Gail’s parents supported her to explain diabetes to teachers in primary school *“it was my primary 4 teacher who first got told. She was a bit like*

shocked and everything because she didn't really know what it was. But um, like my mum and dad explained about hypo's and what to do and everything so she actually went quite well with it really" and later in high school her mother provided information and supplies to school so that she was able to go abroad with them; *"we went on this trip where we went to France, Belgium and Holland. That was alright 'cause my mum had like spoken to some of the teachers and they all understood and they all had my injections on them in case I lost them"*

In primary school Donna's mother had tried to pave the way however, it was felt to have been futile *"my mom had maybe sent in a letter or something just saying she's diabetic you need to do this, this and this. Some of them [school staff] didn't look at them or... some people just said oh ok and threw the letter away or something."*

Erica's parents had gone into primary school with her to let them know about her diabetes, but she recalled continued confusion; *"my mum and my dad, they both came. It was pretty confusing at the time. Um, she [teacher] was ok, she was listening about it 'cause my dad was telling her what to do, and she was listening, but she still...she still didn't quite get it."*

Within school at times a certain member of staff could also smooth the path with other staff for the adolescents when difficulties associated with their diabetes occurred. Andrew talked about his guidance teacher: *"my guidance teacher always seemed to be available to go and talk to, and he would like...he always said to me if I had any problems, any teachers that wouldn't like let me out or anything, I would go and see him and he would sort it out"*. Freya explained that; *"one of the deputy head teachers ...well like I had meetings with him and stuff, he was like understanding that*

'cause I've been ill and stuff, he was like helping me to get like more revisions stuff and ev'rythin' and stuff through that, and he was also like saying to the teachers that I wouldn't be able to do this...like I wouldn't be able to do practical PE sometimes and stuff that. So, he was helpful", and had also had help from her guidance teacher to alleviate problems; "it was like 'oh, you've been off so you've got to catch up in your own time, it's not my fault that you're off' and stuff like this, that's what teachers used to say...t' me, and I used to have to like go to ma guidance teacher and speak to her about it, because I didn't really know how to catch up sorta thing. So then she would say to them that they need to help me more because it's not my fault that I've been off, sorta thing, so it's like changed them."

Gail had had similar support from one of her teachers following a challenging situation; *"I went and told my teacher that I went hypo in the exam and I don't know if I'm going to get a good mark or not and then he said alright I'll help raise awareness of it then. So like then I think he went to the head teacher and something's getting done just now to like help people get more aware of it and that, so that's pretty good"*.

For others their parents helped to explain to their friends or friends parents to make social activities easier e.g. Donna stated, *"my mum'll say to their mum, like if I'm going to a sleepover or something, like when I was younger, and er they'd never actually seen me check my bloods, my mum would say to their mum...just warn them and things like that."* and Erica expressed *"my best friend who's been there for me my whole life ...but my mum like when he was a bit older, mum and dad got his mum*

and dad and him obviously and explained it to them. So now, then he was always there for me.”

This type of support appears to have been generally beneficial for participants reducing the onus on them to keep explaining diabetes to people.

2. Knowledge and Understanding

2.1. Knowledge and Understanding

People knowing and understanding about diabetes made a significant difference to the ability of the young people to successfully assimilate diabetes into their day to day lives. Some of the biggest hurdles to achieving this adaptation came as a result of the action of others due to insufficient awareness, knowledge and understanding.

2.2. School staff knowledge

There was a significant amount of discussion centring on the knowledge that school staff had about diabetes. There was a general impression from the participants that teachers had little knowledge about diabetes, but some were uncertain about the extent of the knowledge deficit. Some believed them to have no knowledge for example Erica who explained *“like every year you get a new teacher, and none of them know what diabetes is, so you have to explain.”* Others were more uncertain including Clare who said: *“Some [understand it] more than others, but...I remember in my old school one of the nurses came in from hospital and gave everyone like a talk on it, so I’m not sure if they’ve done that to the new school, or if they have in previous years which I think which they might have. But, I think they do, like they do know what it is but I don’t really know.”*

Andrew reported *“I have confidence that the nursing staff would all know what to do, I have confidence that if I was in school with my friends, my friends would get someone, and I have confidence that that person [teacher] would get...that if they personally didn’t know what to do, because obviously not everyone knows what to do, they would get someone like the nursing staff who like knows what to do... It’s never like been a concern, like thinking if it went really badly they wouldn’t know what to do, like I’ve never thought about it, but I suppose I would expect that they would know what to do.”*

Others had little confidence in the amount of knowledge that teachers had including Beth who knew that staff at school were aware of diabetes but did not think they would know how to manage diabetic episodes: *“all they’ve been told really is I’ve got diabetes, that’s about it. Like, if I needed the gel, they [teachers] wouldn’t know what to do...but the teachers, I don’t think they would know what to do really.”*

Donna recalled past experiences when staff had exhibited little knowledge: *“in like primary, nobody knew about it...you’d be like ‘I feel low’ [teacher would say] ‘oh what’s up?’ ‘I need to have sweets’ ‘you’ll have to go out of the class to do that’ and you’re only in primary school and you’d think... ooooookay? ‘cause I thought they should know about it”* and recalled the diabetes specialist nurse having to step in after an incident when school staff were unprepared and unable to manage a diabetes emergency in order to give them knowledge *“well it was kinda basically my nurses fault cause she wasn’t happy that that had happened, erm and she had went in and basically shouted at them (laughs) and said ‘you should know this you should know that’ and kinda for once I don’t want to say it, but for once they kinda listened cause*

they had seen what had actually happened and it had just changed and it was just...I thought it was amazing...yeah."

Freya had encountered difficulties with re-assimilating into school following absences due to diabetes as a result of staff members lack of understanding about the condition *"it's like I go back to school, and then it's like...it's better, they just like help me catch up and stuff. But to start off with it wasn't like that, it was like 'oh, you've been off so you've got to catch up in your own time, it's not my fault that you're off' and stuff like this, that's what teachers used to say."*

Given the difficulties that arose through a lack of knowledge it was important for participants to feel secure in the school environment, and it was therefore essential to them that staff knew more about type 1 diabetes and how it should be managed. Without that knowledge difficult situations arose for the adolescents; impacting upon their ability to fit diabetes into school life and manage it successfully. As a result a consistent recommendation made by participants was that teachers increase their knowledge or receive training about diabetes and what to do in case of high or low glycaemic episodes.

Beth suggestion to make school better was: *"just to make all the teachers like a bit more aware of what it [diabetes] actually is, not that just people have got type 1 diabetes, that they know what it is and what to do if something goes wrong. I think that would probably make it a bit easier, like knowing that you'd be ok if anything happened. For the school, probably just to learn a bit more about it and to know what to do if something goes wrong."*

Freya felt that staff did not take diabetes seriously, and believed they needed to understand more about it: *“Like...all the teachers, like ...like should know more about it than... ’cause like they’re kinda just puttin’ it to the side thinking oh it’s not that bad...that big deal, you can’t see anything, sort of thing...So, it’s like...if they knew more ...more about it...it’d be better.”*

Donna agreed; *“Like the teachers need to know how to treat it, they need to be taught about it...Like kinda...not like need to go through a course, but need to know some basic knowledge of it. Like if somebody feels hypo or low...they eat somethin’ sugary, like somethin’ like that. ‘Cause like some teachers you would say that and they’d be like ‘huh?’ Need to eat somethin’ ...kinda they don’t even know what it is. I’ve had one experience where a...I think it was a, erm a reserve teacher and she didn’t even know what it was!”*

Gail felt that teachers lacked awareness and suggested that; *“if a nurse maybe came in and explained it if they just had like all of the teachers and staff go into like a room and then a nurse would come and explain what it is explain how to help it then that would be good.”*

Erica was also of the view that school staff needed to know more: *“I think the nurse at the hospital either has or was going to do like a little class to educate the teachers on diabetes, ‘cause there are kids, like more kids in school with it, and teachers need to understand it more, so I think she’s going to tell them, and teach them about it, but I don’t know if she has or not. So I think it would help if they knew more about hypos and hypers, Um, and if people need to do injections at school, then for them to know more about that as well.”* she also thought it was important for staff to understand

what would help to make managing their diabetes easier and said: *“Maybe just lunchtimes, they need to know that we can’t wait a long time for our lunch. ‘Cause we have to get up at like 7 in the morning and then we have to get lunch at like quarter....well at home it’s like 12 or something like that...probably learn that we can’t wait that long for our lunch um and to let us in.”*

Donna also thought that teachers needed be able to understand that as they matured their ability to self-manage their diabetes changed and they could be trusted to be more responsible for management; *“I think they need to ... learn how to kind of change with it, if that makes sense ...erm...they need to adjust to it. ‘Cause like sometimes you get the teachers who say ‘go down and see the nurse’ and you think I don’t need to I’m...old enough and know how to control and things like that. I think kinda need to be told ‘yes, do know how to treat, just let them treat it themselves’.”*

2.3. Others who understand

A final additional subtheme in relation to knowledge and understanding was that of ‘Others who understand’. Other people who had direct knowledge appeared to make it easier for participants in terms of understanding and support, and gave them a shared language; easing the burden of having to explain it.

Beth discovered; *“there’s one teacher, his son’s got it so I talk to him...I spoke to him about it quite a lot to start off with... so I spoke to him a lot about it. And, um, there was two other of my teachers, they’ve got like mums or sisters or brothers that’s got it, so they were quite, they knew quite a lot about it.”* Freya also reported finding a person with knowledge of diabetes; *“to start off with my guidance teacher, she was really helpful, but she didn’t really know too much, but she did know more*

than everyone else. But then her husband got diabetes, so now she knows loads more about it."

Donna found that having a person with knowledge of diabetes eased the management into her school life; *"teacher let me...let me sit with a big bag of Doritos and an apple juice carton once. I was like oh I feel low, and she was like ok... erm 'cause I think her ...a relation of hers was diabetic...so she kinda knew about it as well...kinda background. So she was like yeah ok just do what you need."* She also described how finding out that a peer knew somebody with diabetes was a positive experience, accompanied by a sense of relief; *"Somebody tell me they know someb'dy who's got it. It kinda makes me feel happy that I don't have to go and explain it, and that they've kinda already had an experience with it...When somebody just tells ya I know somebody, you're just like 'thank the lord, hallelujah!' somebody else like has it, and like you don't have to say, you don't have to go 'oh I feel low' and somebody'll go 'what's that?', 'I need somethin' t'eat'... you don't have to go into explanations, they already know what's happening, and you're just like yey! It's like you don't feel like you're on your own, you know that there is people out there the same as you...and you can you can share experiences and things like that."*

Andrew recalled becoming aware of peers with diabetes and found it beneficial; *"I went back to school and found out the actually two of the people I knew in my year had diabetes and we kinda, I suppose you never really bother to think about it. I would talk to them at the start, like just asking them things like what they would do."*

Gail was also pleased to discover peers in school with diabetes in terms of emotional support; *"I found out that more people in the high school had got it, so I could like*

...speak to them about it and everything...It was quite good speaking to someone about it who actually has it. You can just like relate really easy...people who don't have it don't really understand it as well as if you would have it" and also practical help at times; *"it is quite helpful cause if I forget to take stuff to school with me quite a lot if I have a hypo or anything I've got a couple of people I can ask like 'can I get a dextrose?'"* This positive experience had even led her to being open to talk to other young people who were newly diagnosed; *"I'd definitely speak to someone who is newly diagnosed about it now like I have done a couple of times like explain like it's not actually that bad like if you control it then you get used to it like it's not the worst thing in the world. But it is useful to have people to speak to."*

However, the experience was not as positive for other participants who were indifferent about knowing other people who had diabetes such as Clare who said: *"Although in my last school it was me and one other boy in the year above [who had diabetes]. Obviously I'm quite new to this school, well it's been a year now, but I don't know if anybody else has it. It's quite a small school anyway, so if there was it'd probably only be one other person, but...I don't really...even if there was somebody else with diabetes, it wouldn't make a difference."*

Freya's feelings were mixed about knowing other people with diabetes, but at times she found it frustrating when comparisons made her feel bad: *"well I speak to one of the people in my year who's got it, so in a good way it is, 'cause you can speak to them more about it, in a bad way it's like you don't really want to know how they're able to like control it and stuff, because like then you get annoyed because you're doing stuff so good, but...and they're still like not doing as good stuff as you, but*

then they're not ending up in hospital with ketones and everything and stuff, so it's like half and half."

3. Standing out

Young people were keen not to stand out from others, not unexpectedly at this developmental stage. Unfortunately diabetes is quite an obtrusive condition requiring injections and other management strategies, as a result strategies were introduced in an attempt to minimise the attention drawn to the adolescents. However, at times these were unhelpful in terms of successfully managing their diabetes in terms of physical wellbeing.

4. Adjusting and accepting

4.1. Getting on with it.

It was helpful for peers not to make a fuss about their diabetes and just let them do what was necessary to manage the condition. Teachers could also play a role in helping participants to manage their diabetes by supporting them to undertake management activities without any fuss.

Some teachers appeared to be more attuned to the needs of the young people in relation to discretion with diabetes management. Clare had had positive experiences and described *"if I'm hypo in class the teachers will be really understanding and they'll just say if I'm ever hypo don't even bother putting your hand up because obviously you need to eat, and just eat whenever you want and I'll understand that you're hypo and you need to eat. So...so that's always been a good thing"* and that previously teachers had become accustomed to her needs *"at my old school, if I was hypo, em my teacher, she was really good... she was really understanding, 'cause I*

was hypo quite a few times, and I'd be 'I'm diabetic I've got to have something to eat' she'd be like 'oh ok that's fine go and grab what you have to do', and then eventually she just said 'you don't even need to tell me if you're hypo you just bring food and I'll know that you're hypo' so she was really good."

Gail had also found that teachers had become more attuned to her symptoms and this had been helpful; *"like he can tell, it's got to the stage where he can tell when I'm low...then but sometimes like I don't speak, I'll just like wait until the period is finished, but he can tell and he'll be like he'll get one of my friends to like go somewhere with me and that."*

4.2. Becoming responsible for diabetes

Becoming more responsible for diabetes management had enabled participants to integrate diabetes into their lives more successfully. Clare explained, *"I picked my own regime, like what insulin I'd have when, and like what time, and then it's like quite an unusual one, but then it works really well... 'cause what helps as well I've got so much responsibility over it, I control everything... 'cause I would like hate to be reliant on my mum like my entire life, or even the age I'm at right now."*

Freya also found it beneficial: *"When I started doing ma injections maself I stopped going early [lunchtime] 'cause it meant like you didn't have your friends to go to lunch with and stuff. 'Cause nob'dy else was allowed out with you sort of thing. So, I just stopped doing that."* As did Donna *"... it was right you've got to be sensible you've got to learn how to do it...if something happened you've got to sort it"* and parental support enabled her to, *"'cause that's what mum and dad have always tried to do, they've kinda always tried...to get us independent."*

Erica reported being restricted somewhat due to relying on family for diabetes management *“diabetes can stop me with things like that, ‘cause I mean...well I was new to doing injections, I was on 3 times a day...and then it’s like in my hip and I can’t really reach there so it’s quite difficult...so in a way it kind of stops me from doing overnight stuff, um like going to sleepovers and whatnot.”*

And Gail described her fears about having to take on the responsibility; *“I think I was most scared about going into high school not because it was the big school and it was all the big people but because of the diabetes and everything, that was what scared me the most being on my own with it.”*

4.3. Becoming more comfortable

There was a process that participants went through of becoming more comfortable both with diabetes itself and with letting people know about it.

Andrew described : *“‘cause at that time I wasn’t overly comfortable with it, so it was...it was quite embarrassing sometimes, but like now I don’t bother about it really, and there’s been nothing really that’s happened really, it’s all been ok. Now I just feel confidence myself, and if I have a problem I’ll like...mum knows a lot about it so I’ll just talk to mum... I don’t really find any problems that I can’t know or find out the answers to.”*

For Beth it had been difficult initially but she had become more accustomed to it:

“when I first got it I was really like I was getting quite worked up about it. And I wouldn’t let anyone else like do it apart from my mum and my dad, but if someone else was in the room, I’d ask to leave. so...yeah, I don’t know...it’s just there’s no point in like messing about like that, you just get on with it...it’s ok now, I just sit in

the canteen and do it [injection], but before I was really like self-conscious about it. Now it doesn't bother me that much."

Other participants had felt awkward initially too, Freya described: *"Going back to school was quite hard 'cause like nobd'y really knew anything about it, so it was just like I was going back as ma normal self...sort of thing, but I had to like leave class early at lunchtimes and that because ma mum had to do ma injections...But it wasn't too bad."*

Gail expressed difficult emotions associated with the diagnosis; *"I just don't make a big deal out of it. I've always been like that really. Like when I was little I felt like I used to be kind of ashamed to have it I don't know why. It just made me, like I said it makes me feel like the odd one out and I don't like that feeling"* and shared the anxiety she had felt about the responses her revelation would receive; *"it made me kind of upset when I had to tell people about it, I thought people would judge me really bad and all this I don't know why but I'd always thought that I thought people would erm take the mic out of me."*

Those diagnosed at an earlier stage were able to recall becoming used to having diabetes including Clare who explained: *"Well obviously I'd rather not have it. I think it helps having it from such a young age, I grown...I've like kind of grown up with it. Then, it can be annoying waking up at like three in the morning having to have lemonade and stuff if I'm hypo. Em, but... like you get used to it. Like just now I just...you know stab yourself like the injection ...you get used to it."*

Donna had found the process a little more challenging; *"when I was younger I always used to think it was an excuse... it was just something that aw I'm lucky to*

have this I'll go and have sweeties and things like that but kinda as I've got older I've realised I can't do that cause it kinda messes ...it doesn't mess your body up but (sigh) you find it harder to control it more...and I think it's (pause) ...kinda been a difficult journey trying to get up because when I was younger I was allowed little sweeties but as you get older you're told that you handle it yourself and you're like (pause) but I just wanta eat sweeties (laughs) but it's like no, you can't do that you it's like you canna be young again...erm so it's (sigh) quite I think growing up with it's quite... difficult"

Participants who had been diagnosed later in life expressed a concern about sharing it with others initially, and had had to become used to the diagnosis themselves in order to become more comfortable with telling other people about it.

Beth described the process that she had gone through: *"well I was really conscious about it [returning to school following diagnosis]I didn't want anyone to know, Um, but I had to tell my teachers, so that's quite embarrassing to start off with, but once I'd done it a while it was ok. I'm not really that bothered about it now, so I just go up and say um 'I've been told to tell you that I've got type 1 diabetes, so if I hypo I'll need to eat in class or I'll need to leave, and before lunch I'll need to leave 5 minutes early to go and do my injection' so..."*

Freya reflected upon the process of telling people; *"well when I was first diagnosed it was really just who I was in the class with an' that, they were like being nosy obviously...so they were like why you going to the doctors, and I said like I was going to get checked for diabetes and like when I came back to get my bag and stuff they were like have you got diabetes an' that, so I couldn't really just like not say*

anything, I think I was just like 'yeah, I've got it'. It's doesn't really bother me when people speaking to me about it or that, I just answer their questions, if they've got questions or that. It was just mainly the people that were in this class at the time that I had to leave, otherwise I prob'ly would've just told like ma best friends rather than everyb'dy else, but...it doesn't bother me anymore."

Erica still found it difficult to explain it as at times she felt uncertain that she really understood it herself: *"I still don't quite get it; I just said that you know... if I get dizzy, if I just walk off and get something out of my bag and prick my finger, don't get scared. Um, that's the...that was what basically I said then, and now I just go like...in the middle of class if we're doing something I'll probably have to walk out at some point to do it, and they're like 'oh! Why's that then?' and I was like...unless I pass out then yeah... They don't know what it is though. It's...I've tried explaining it to them, but they still don't know what it is."*

5. Over and over

A final theme emerging from the interviews was that of 'over and over' which represented the frustration that participants felt associated with the constancy in relation to explaining about diabetes and its necessary management. The theme encompassed participants having to repeat the process of telling people when they moved between schools or years, or having to remind people, but also related to answering questions about their diabetes.

Andrew had experienced both aspects of the theme, he described *"'Cause like I noticed like the first couple of times, even though I'd given a letter, they would like forget, and you'd have to remind them. like because I've got to ask the teachers to go*

out five minutes early, like some of the teachers forget that you've got to go out five minutes early and forget why, and you have to explain again." And was also irritated when; *"It was like multiple questions bombarding you, and that was...that would get annoying ... they didn't like make a huge fuss about it they just asked me, but repeating the same answer to the same question over and over again got repetitive."*

Erica described the frustration of the repetitive process: *"other days it's just its annoying having to constantly tell the teachers, and I mean even if you told them once you have to constantly remind the same teachers that you have to get your lunch"* and the annoyance of explaining it in contrast to the relief that came when people already knew; *"so you have to explain every single year, and it's so annoying. I mean especially at [high school] because you have all different teachers, so having to go class to class, and explain to every single one of them what it is, and if you get the same teacher twice in like...same teacher...teacher for two years or three years, it's like much easier 'cause like you've already told them, so you don't have to tell them that, but if you get a new one you tell them...tell them and it's like 'what's that then?', and I'm like 'oh god!'"*

Gail was also tired of the repetitious nature of explaining; *"I would just want people to know what it is really because even though people know that I've got it they still ask what is it how does it affect you why do you have to inject why do you have to do this. Just for everyone to know so that they wouldn't have to ask me. All like pupils and that because it gets tiring explaining it again and again and again and I've been doing that since primary four."*

On the other hand, although she had gone through a similar process Donna felt that having to explain it over and over had been beneficial; *“you had to explain and explain, suppose it was kinda learning how to explain it that helped you there, through that kinda six years when you had to keep explaining it and explaining it...it’s probably when I learned most about it, because I had to explain it to everybody. I would always have to go ask ma mum how to kinda explain it to somebody, and she would always be like ‘right, this is how to explain it, this is how to like kinda say it’ kinda thing, and she would like teach me a bit more each time. So like then I was ‘so I have diabetes, I have to eat something if I feel shaky’, but now I would say like ‘hi, I’ve got diabetes, if I look like I’m about to faint or I’m sleepy or something like that, I need to have somethin’ t’ eat, and if this doesn’t work, have this’, and it’s just kinda the progression. It’s kinda really helped me.”*

Feedback on the study provided by the diabetes specialist nurse and the secondary school teacher

As part of the process of methodological rigour two professionals working within the field of diabetes care, and education were contacted to elicit their views on the study outcomes and the themes that had emerged through the analysis process.

Upon discussion with the diabetes specialist nurse the following observations and comments were elicited. The theme of support was reported by the nurse to be very typical of what young people described to her in the school setting, with guidance being the main port of call for any discussions of their problems in school. The nurse reported that there were *“always on-going issues with particular teachers who think*

others know”. In terms of peer support the nurse had found support to be to the detriment of friendships for the young people. And in relation to practical supports within the school setting the nurse reflected that it “*works for some and not for others. Notice it depends on individuals and how they feel about their diabetes.*”

The theme of Knowledge was discussed and the nurse acknowledged a difficulty particularly with relief and teachers covering others classes who don’t know pupils. She reported trying to manage this difficulty by encouraging all children to carry a laminated card with their details and Diabetes needs on it; however, not all children use it. Provision of diabetes awareness training by herself in secondary schools was described as being in place, but achieving variable attendance and was seen as being an ongoing need.

In terms of the theme of standing out the nurse reported lots of issues around this and the risks that young people put themselves at so as not to be different. She described the issue as a significant problem and one which is important for safety, and therefore needs to be discussed further and young people need to be encouraged to participate in safety aspects of their diabetes care.

On discussing the theme of Adjusting and accepting the nurse was surprised that the overall experiences were positive, she felt that some children would not adjust in school and therefore their regimes had had to be managed so as not to impact on their school day.

Overall the nurse commented that there was “*a lot of ignorance around diabetes in schools as well as in public! Schools wish the management to be clear cut and diabetes is not.*” She also reported finding some of the insights from the study helpful

and that as a result she will now be revisiting children within their schools to try and discuss on-going issues around their diabetes in schools and to attempt to further *“provide individual diabetes care according to the needs of child.”*

The teachers' comments were that it was an interesting study and gave a real feel for the experiences of the young people. The teacher reported that she believed that she knew about diabetes but that hearing the study outcomes and the experiences of the young people really raised her awareness of some of the issues that the young people faced and the challenges of managing their diabetes within school. However, she reported that it was difficult as a teacher too because each child has a different approach and that it can be hard to keep track of everybody. The teacher reported that she believed herself to have had knowledge of diabetes but really not about the intricacies of management and as a consequence would ask more about it on the forthcoming first aid training she was attending. She also reported that she would be more likely to try to attend any training given within school by the diabetes team in the future.

Additional discussion

Diabetes is a difficult and demanding condition to manage. A number of difficult emotional experiences were described by participants during the study. These experiences were associated with having the condition and the regimens involved in its management, but also emerged as a result of the social difficulties that stemmed from having to manage it within the school environment.

Being given the diagnosis instigated the journey towards acceptance that began with feelings of discomfort and embarrassment amongst other emotions. It is recognised that 'Emotional and psychological needs may be greater at key times such as diagnosis, the developmental stages during childhood' (Diabetes UK, 2010b, p6) and that was reflected by the accounts of participants in this study. The process of telling people was also described as being anxiety provoking by some of the participants and was met by different receptions from the audience which impacted on their likelihood to tell others.

It was most helpful for participants to feel accepted and to be allowed to get on with what they needed to by their peers; however, that had not been the experience of a number of participants who had come up against negative responses to the extreme of being bullied, a potential risk factor in developing self-esteem difficulties or a depressive episode. A previous study (Dickinson & O'Reilly, 2004) had also found that adolescents felt the desire to be part of their peer group and that diabetes had unhelpfully made them stand out, and it is also known from the study by Warrington & Younger (2011) that bullying within the school environment can be difficult for adolescents and lead to feelings of demoralisation and depression.

Participants in this study as in a number of others (Carroll & Marrero, 2006; Christian *et al.*, 1999; Davidson *et al.*, 2004; Dickinson & O'Reilly, 2004; Huus & Enskar, 2007; Wang *et al.*, 2010; Wilson, 2010) viewed the sense of difference that resulted from having type 1 diabetes negatively and wanted to alleviate it. The feeling of difference from peers is important at this stage in their life and may result in a threat to their self-concept which would be psychologically detrimental (Dovey-Pearce *et al.*, 2007). As a result, participants had implemented strategies to help them to minimise the attention they received and consequently fit it more seamlessly with their peers. Avoidance of situations compromising their image was also a practice that was found to be commonly adopted by adolescents in general within the school environment (Warrington & Younger, 2011). In this study as in a number of others (Hawthorne *et al.*, 2011; Huus & Enskar, 2007; Wang *et al.*, 2011) participants reported compromising on their diabetes management or delaying it so as to avoid calling attention to their diabetes and appearing to stand out.

Knowledge and understanding of peers was reported to be helpful; it reduced the sense of being different that participants felt. Peers' knowing was beneficial for participants as it provided them with a sense of security, this was a perspective shared by participants in the study by Christian *et al.* (1999), and it allowed them to fit in with the adolescent culture which was of vital importance given their developmental stage.

Unlike participants in some studies (Christian *et al.*, 1999; Wilson, 2010) who had described being unable to do things with or like their peers as a consequence of their diabetes, in this study peers were generally described as being accommodating and

allowing them to undertake necessary management helping it to fit better into their lives.

Practical peer support was reported to make it much easier for the young people to adapt to their diagnosis and facilitate the integration of diabetes into their lives.

Being aware that other young people knew what to do if they became unwell was comforting to participants, even if they felt confident in their own abilities, as it meant they were less alone with the condition. Other studies had found similar response by their participants; Wang et al. (2010) reported that participants had *'recognised the importance and the need to have classmates around them who knew about their diabetes'* (p. 261) and Carroll & Marrero (2006) found that friends were positively perceived and were helpful if they were ever in trouble.

Having peers with diabetes who could be approached to discuss things with was helpful for some participants. It provided the opportunity to learn from others and check things out with them, and even meant a backup source for forgotten dextrose. This resource was particularly helpful for some participants in the early stages of adjusting to diagnosis, however, as the young people became more confident in their own abilities that source of support was utilised less often, particularly when they were peers rather than friends. One participant even reported being willing to provide that support to other young people who had recently received a diagnosis as it had been so helpful to her. This would suggest that a facility such as a diabetes peer mentor might be a helpful provision for young people around the time of their diagnosis; both to provide support and advice and to reduce the feeling of isolation and difference that may emerge around that time.

Interview discussions also encompassed the specific experiences of diabetes within the school environment. For many it was repetitious in terms of telling people, answering questions and having to remind them. Often giving teacher's information about diabetes, especially within a high school environment, was an extensive and stressful process and one that had to be repeated on a yearly basis. For that reason participants expressed a sense of relief when they had the same teachers in subsequent years as it typically meant them not having to explain it to them again. Given that depression can be associated with experiences of diabetes that are stressful and upsetting (Delamater, 2009); it would suggest that a procedure for reducing this frustrating and stressful process would be beneficial to the young people's emotional wellbeing.

In relation to that repetitious and frustrating necessity to have to explain diabetes extensively, it was helpful when a specific member of staff to put themselves forward as a sort of 'champion' for some of the participants. That person could be particularly helpful by co-ordinating the distribution of information to other members of staff prior to the young person starting, generally raising staff awareness and solving any difficulties that arose within school as a consequence of their diabetes. Having someone who could be relied upon to provide understanding and support within school if or when it was needed was reassuring for the participants, so perhaps the 'champion' could also assume that role.

The actions of others including implementation of proactive strategies were seen to be helpful in reducing its impact upon participants within school. Examples of this were given by the participants including seating arrangement in class, planning for

exams and an early pass for lunch. The practical strategies that were put into place were viewed as being most helpful when they were mindful of the young person's peer relationships and minimised the attention that was focused upon them.

It was important that knowledgeable support be available should it be needed, however, being forced into accepting unnecessary help was frustrating. Support from people who had little knowledge was found to be counterproductive and left the young people feeling insecure in the environment. Becoming more responsible for their diabetes management had enabled young people to become more independent, an age appropriate developmental process, and could be facilitated by teachers and peers through allowing the young people to get on with what they needed to unquestioned and respecting their ability to do so.

Opinions of the participant varied in relation to the helpfulness of others who had diabetes or were close to people who did. It appeared to help diabetes to fit into school better if staff had direct knowledge through people close to them having diabetes. It cut through the need for any explanations; giving an understanding that was beyond the theoretical, provided a share language, and smoothed the path for timely and appropriate management within school.

Coming up against the lack of knowledge and prejudices of others had been difficult for a number of the participants. This would suggest that increasing other people's knowledge would play an important role in maintaining the young people's mental and physical health. Participants all had an opinion regarding the knowledge of school staff in relation to diabetes and its management. The majority were of the belief that on the whole staff lacked knowledge. This is a difficulty that has

previously been identified by young people (Carroll & Marrero, 2006; Christian *et al.*, 1999; Hawthorne *et al.*, 2011; Hayes-Bohn, 2004). Amillategui *et al.* (2007) discovered that 66% of the parents in their study believed teachers would be unable to recognise a hypoglycaemic episode, and Pinelli *et al.* (2011) found that 59.6% of school personnel reported having had no specific training on diabetes and only 26.3% felt that their school would be able to manage a diabetic emergency, concerning statistics considering the possible ramifications for the young people involved.

The consequences of that lack of knowledge varied for the participants; for some it was a case of explaining it to teachers, for others it was feeling unsupported and uncared for and for others again it was a concern for their physical wellbeing. In some circumstances it had also led to participants being embarrassed by teachers in front of their peers, something that had been experienced by young people in other studies (Huus & Enskar, 2007; Schwartz *et al.*, 2010). Such experiences would be emotionally difficult for the young people; leading to feelings of stress and anxiety, and could increase their likelihood of non-adherence to management within school.

Some of the participants in this study had directly experienced the unhelpful consequences of a lack of knowledge which had led to them feeling under pressure to be self-reliant, but also in one case to feel further overwhelmed in relation to schoolwork.

There was a significant concern for participants about school personnel's lack of knowledge in relation to diabetes emergencies e.g. hypoglycaemic episodes. During such episodes when they were physically unwell and possibly incapable of helping

themselves it was difficult and even frightening for participants to think that the people in school who should be in a position to help them would not have the ability to do so as a result of unfamiliarity with the condition and its management.

Unsurprisingly then the overwhelming consensus amongst participants was that staff at school should know more about type 1 diabetes and its management. Suggestions from the participants included that this information should be provided by a diabetes nurse, and this was supported by teachers' suggestions from the Pinelli *et al.* (2011) study when 60.8% of them said they should participate in specific training.

An attempt was made to invite participants to comment upon the themes and conclusions drawn by the chief investigator during the analysis process. Invitations were sent out however none of the young people chose to respond. It is possible that the lack of response to the invitation was due to the time of year, being the beginning of December, but it was therefore not possible to elicit their views on the interpretations made by the investigator of their experiences.

Whilst the IPA approach does not specifically include a return to seek participant feedback as part of the validity process of the research, it is part of a methodology advocated in qualitative research and is therefore a potential area of deficiency of the study. Upon reflection having no feedback on the outcomes from the participants is a weakness of the study, however, the reflections of the diabetes specialist nurse who described having heard similar stories and encountering similar difficulties e.g. in relation to the knowledge of teachers supported the results of the analysis.

Whereas the focus of previous studies (e.g. Anderson *et al.*, 2002; Farrell *et al.*, 2004) has often been on the factors affecting glycaemic control, this study set out to

explore adolescent experiences of having diabetes, although it also builds on the knowledge that had already been gained through previous qualitative research (e.g. Wang *et al.*, 2010).

The outcomes of previous studies including those within the systematic review, and included within the bridging chapter provided evidence of the difficulties that young people with diabetes experience in their lives. The reports of parents and some young people (e.g. Nabors *et al.*, 2003; Pinelli *et al.*, 2011) highlighted the perceived lack of knowledge of staff within school of type 1 diabetes and its emergency management. Participants in the current study also reported this concern however, further investigation and interpretation of their experienced led to an increased understanding of the importance of this lack of knowledge for the young people and its impact upon them.

The implications of teachers' lack of knowledge were twofold; it meant that the young people felt solely responsible for their wellbeing during the school day, an added pressure for many within a difficult environment. It also meant that many had experienced uncomfortable and potentially embarrassing situations or feared that they would and therefore altered their behaviour in terms of diabetes management to minimise the likelihood. Most of the behaviours of the young people in this study was found to be in the interests of fitting in with their peers, be it adopting an adapted management routine with medical support, or putting off management in a less adaptive manner.

Implications for practice

The outcomes of the study would suggest that adolescents have individual but somewhat consistent experiences of managing type 1 diabetes within the school setting. The experiences that the young people had were social in their nature and were dependent on the actions and responses of the people within the environment. For that reason then, most of the recommendations emerging from the accounts of the participants are associated with what other people can do to help them.

Within schools having a ‘champion’; one consistent knowledgeable member of staff whom they can approach for support and with any difficulties, and who could act as a liaison with other staff members would appear to be beneficial for young people. It would be useful for that person to have an awareness of the difficulties that young people with diabetes can experience and the value that they set on being supported to fit in with their peers and not be isolated further by reason of diabetes management. The feedback given by the secondary school teacher following the study analysis was that it was helpful to hear the experiences of the young people as it helped her to understand some of the difficulties young people experience, highlighting the need to know more and prompting a desire to understand the condition better.

Alongside this a source of knowledgeable and practical support for their diabetes management that was available if it was deemed necessary was something which enabled the young people to feel secure within the environment. It is therefore recommended that such a facility be available within school, and it should be made apparent to pupils where or whom that would be.

Given the general frustration and stress involved with repeatedly telling staff about their diabetes, having a procedure in place in school to provide information to staff in advance of a pupil with diabetes attending class would appear to be something that the young people would find beneficial; particularly if it was retained by the staff.

Generally it was useful for young people if practical management strategies were pre-arranged and did not come about as a result of previously unsuccessful experiences. Strategies were deemed to be most favourable when they were discrete and/or prevented young people feeling further isolated by their diabetes. It would therefore be helpful for strategies to be discussed in relation to the needs of the individual. An overall recommendation would be for schools to be knowledgeable and more accommodating of the individual's diabetes management strategies and perhaps a health professional could facilitate a meeting between school personnel and the young person and their family following diagnosis, or at the time of transition to the school, to discuss diabetes and the individual needs and management plan for the young person.

A more general, but overwhelmingly supported, recommendation would be that members of staff within schools receive training about type 1 diabetes and its management and that perhaps this be provided by a specialist. The specialist nurse contacted for feedback reported providing this facility locally with varying levels of take up from staff. It is possible that providing teachers with the results of the study highlighting the difficulties for young people and the need for them to understand diabetes better, such as was done with one teacher, would improve training take up and benefit young people in school. It is recommended that schools should promote

education for their staff around diabetes and its management, and facilitate the uptake of training provided by external healthcare staff in any way possible.

Given the prevalence of psychological difficulties in young people with diabetes, and the social and emotional difficulties within school (including feelings of anxiety and isolation) described by participants in this study, it is recommended that staff within school be made aware of the potential for psychological difficulties and be trained in recognising these. Alongside this is the recommendation that psychological treatment be made available to all young people with type 1 diabetes and be publicised to them. Studies (e.g. Harkness *et al.*, 2010; Viner *et al.*, 2003) have shown that psychological treatment can have positive impacts upon both psychiatric difficulties and self-management of diabetes, and psychological treatment availability is recommended within the NICE (NICE, 2004) and SIGN guidelines (SIGN, 2010) on diabetes.

In terms of healthcare professionals working with young people, it is important for them to understand where the difficulties might arise for the young people in relation to diabetes care. It would be important for them to facilitate non-judgemental discussions with young people to understand the pressures they experience within the school environment and to develop helpful strategies or adjust management plans to adapt to their changing needs and fit effectively within their lifestyle.

The final suggestion arising from analysis of the accounts is that as young people often benefit from knowing peers who have diabetes it might be helpful for them to have a peer mentor, and even if it is possible, for them to have one within the school who has experience who can help them to adjust and answer questions.

Limitations of the study, and potential areas for future research.

The strengths of the study are that it is in line with current recommendations that the views of young people be elicited in relation to developing diabetes service provision and understanding how to meet their needs. The style of this study has enabled the establishment of a unique perspective and understanding of the experiences of adolescents with type 1 diabetes in school using an individual semi-structured interview process and IPA approach; however a disadvantage of this approach is that it is time consuming and therefore not open to large numbers of participants. As a consequence participants were drawn from a relatively small geographical area and therefore may not be representative of the views and experiences of young people in other areas.

Recruitment and interviewing for the study took place during the spring and early summer period at a time when young people would typically be involved in examination processes at school. It is possible that this was detrimental to the uptake due to the possible additional stress that study participation might cause them. A longer recruitment period outside of examination times would therefore be recommended for any future research.

The approach from an unknown clinician to participate in a study could also have been a problem for young people and prevented them from participating. It is also possible that those young people who did participate did not talk about everything due to not feeling comfortable around an unknown interviewer. However, it is also possible that the study being independent of their existing diabetes service was beneficial and allowed participants to discuss issues, made anonymous in the report,

that they would have been unable to discuss with a clinician involved in their care for concern about potential difficulties their comments might cause for them.

A total of seven adolescents participated in the study, which was fewer than the proposed 10 participants that the study was granted ethical approval for, however was 1/3 of the total population which is a strength. This could be seen as a weakness of the study, however, it is not unreasonable for IPA research studies to use smaller sample sizes, and in this study there were felt to be sufficient cases for meaningful themes to emerge within which there were variations.

A final area of potential weakness within the study is the presence of a single interpreter of the transcripts with the possible outcome being that the analysis is too subjective, and presents the views of what the novice IPA analyst thinks the participants are thinking. It was acknowledged by the investigator that the lack of a second investigator during interpretation was a potential area of weakness and therefore to ensure rigour and validity in the analysis process she attended regular supervision to reflect on the process of analysis and discuss the emerging themes.

Given the potential areas of weakness within this study, areas for potential future research include; the replication of the research within another region with a larger and more diverse sample, the inclusion of additional analysts or the use of a computer software package for analysis, and the use of a known clinician to approach the participants initially.

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Appendices

Appendix Number	Document	Pages
1	Letter of approval NRES Committees – North of Scotland. Letter of approval for amendment.	122-129
2	NHS R & D Permission.	130-131
3	Letter of Invitation – Young person.	132-133
4	Letter of Invitation – Parent/Guardian.	134-135
5	Participant information sheet.	136-139
6	Participant Opt in slip.	140
7	Young Person Assent Form.	141
8	Parent/ Guardian Consent Form.	142
9	Interview Schedule.	143-144
10	Example of Transcript Analysis	145
11	Sample supervision notes	146-150
12	Review of qualitative methodology using CASP & criteria for acceptable IPA (Smith, 2011)	151-152
13	Invitation to participate in post study feedback interview.	153
14	Author Guideline: Pediatric Diabetes	154-162
15	Author Guideline: Diabetes Research and Clinical Practice	163-166

Appendix 1. Letters of approval NRES Committees – North of Scotland.

Re-issued on 14 June 2012 – updated attendance table as Dr Hold was not included in the list of those present.

NRES Committees - North of Scotland

Summerfield House
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15 February 2012

Miss Sara Yule
Trainee Clinical Psychologist
NHS Grampian
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The Glassgreen Centre
ELGIN
IV30 6GQ

Dear Miss Yule

Study title: A Qualitative Analysis of the Experiences of Coping
with Type 1 Diabetes in School; A Teenage Perspective.
REC reference: 12/NS/0014

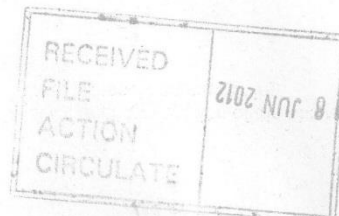
The Research Ethics Committee reviewed the above application at the meeting held on 09 February 2012.

Ethical opinion

The members of the Committee present gave a favourable ethical opinion of the above research on the basis described in the application form, protocol and supporting documentation, subject to the conditions specified below.

Thank you for attending the meeting.

- The Committee felt that you had done an excellent job of your resubmission.
- The Committee would like the 'opt-out' option removed from the 'opt-in' slip. You agreed to this.
- The Committee asked that the information about self harm be removed from the Participant Information Sheet. You agreed to this.
- The Committee asked that in the parent letter you change 'child' to 'son' or 'daughter' to reflect the age group of the participants. You agreed to this.



Re-issued on 14 June 2012 – updated attendance table as Dr Hold was not included in the list of those present.

Ethical review of research sites

NHS Sites

The favourable opinion applies to all NHS sites taking part in the study, subject to management permission being obtained from the NHS/HSC R&D office prior to the start of the study (see "Conditions of the favourable opinion" below).

Conditions of the favourable opinion

The favourable opinion is subject to the following conditions being met prior to the start of the study.

Management permission or approval must be obtained from each host organisation prior to the start of the study at the site concerned.

Management permission ("R&D approval") should be sought from all NHS organisations involved in the study in accordance with NHS research governance arrangements.

Guidance on applying for NHS permission for research is available in the Integrated Research Application System or at <http://www.rdforum.nhs.uk>.

It is responsibility of the sponsor to ensure that all the conditions are complied with before the start of the study or its initiation at a particular site (as applicable).

You should notify the REC in writing once all conditions have been met (except for site approvals from host organisations) and provide copies of any revised documentation with updated version numbers. Confirmation should also be provided to host organisations together with relevant documentation

Approved documents

The documents reviewed and approved at the meeting were:

Document	Version	Date
Covering Letter		17 January 2012
Interview Schedules/Topic Guides	1	12 January 2012
Investigator CV – Sara Yule		17 January 2012
Letter from Statistician		15 January 2012
Letter of invitation to participant – Parent/Guardian	1	13 January 2012
Other: Supervisor's CV: Emily Newman		17 November 2011
Other: Letter of Invitation: Young Person	1	04 January 2012
Other: Young Person Opt In Slip	1	04 January 2012
Other: Unfavourable Opinion Letter		12 December 2011
Participant Consent Form: Parent/Guardian	1	04 January 2012
Participant Consent Form: Young Person Assent Form	1	04 January 2012
Participant Information Sheet	1	14 January 2012
Protocol	1	13 January 2012

Re-issued on 14 June 2012 – updated attendance table as Dr Hold was not included in the list of those present.

REC application	9857 9/283 793/1 /149	19 January 2012
Referees or other scientific critique report		14 November 2011

Membership of the Committee

The members of the Ethics Committee who were present at the meeting are listed on the attached sheet.

Statement of compliance

The Committee is constituted in accordance with the Governance Arrangements for Research Ethics Committees and complies fully with the Standard Operating Procedures for Research Ethics Committees in the UK.

After ethical review

Reporting requirements

The attached document "After ethical review – guidance for researchers" gives detailed guidance on reporting requirements for studies with a favourable opinion, including:

- Notifying substantial amendments
- Adding new sites and investigators
- Notification of serious breaches of the protocol
- Progress and safety reports
- Notifying the end of the study

The NRES website also provides guidance on these topics, which is updated in the light of changes in reporting requirements or procedures.

Feedback

You are invited to give your view of the service that you have received from the National Research Ethics Service and the application procedure. If you wish to make your views known please use the feedback form available on the website.

Further information is available at National Research Ethics Service website > After Review

Re-issued on 14 June 2012 – updated attendance table as Dr Hold was not included in the list of those present.

12/NS/0014

Please quote this number on all correspondence

With the Committee's best wishes for the success of this project

Yours sincerely

Carl Irvine

Dr Alex Johnstone
Chair

Enclosures: List of names and professions of members who were present at the meeting and those who submitted written comments
"After ethical review – guidance for researchers"

Copy to: University of Edinburgh
NHS Grampian R&D Department

Re-issued on 14 June 2012 – updated attendance table as Dr Hold was not included in the list of those present.

North of Scotland Research Ethics Committee (2)

Attendance at Committee meeting on 09 February 2012

Committee Members:

Name	Profession	Present
Mr Stuart Bale	Lay Member - Retired HSE Manager - Shell	Yes
Dr Hanne Bruhn	Research Fellow - Psychology	No
Dr Jennifer Caldwell	Senior Lecturer in Occupational Therapy	No
Dr John Callender	Associate Medical Director	Yes
Dr Sarah Christie	Lay Member - Reader in Law	No
Mr Gary Cooper	Quality Assurance Manager	Yes
Dr Medhat Ezzat	Consultant Neonatologist	No
Dr Fiona Hitchman	Observer	No
Dr Georgina Hold	Senior Lecturer – Microbiology	Yes
Dr Alex Johnstone	Chair & Senior Scientist in Human Nutrition	Yes
Dr Petr Kalous	Consultant Neonatologist	No
Miss Rhoda MacKenzie	Clinical Teaching Fellow - Vascular Surgery	No
Dr Mandy Moffat	Research Fellow - Psychology	No
Dr Jeremy Morse	Manager of Clinical Skills	Yes
Dr Ruth Stephenson	Vice Chair and Consultant in Anaesthesia	No
Mrs Juliette Watson	Quality & Training Manager	No
Mrs Fiona Watson	Lay Member - Ex Company Director	Yes

Also in attendance:

Name	Position (or reason for attending)
Mrs Carol Irvine	Ethics Co-ordinator
Dr Rachel Venables	Scientific Officer

NRES Committees - North of Scotland

Summerfield House
2 Eday Road
Aberdeen
AB15 6RE

Telephone: 01224 558458
Facsimile: 01224 558609
Email: nosres@nhs.net



22 November 2012

Miss Sara Yule
Trainee Clinical Psychologist
NHS Grampian
The Rowan Centre
The Glassgreen Centre
ELGIN
IV30 6GQ

Dear Miss Yule

Study title: A Qualitative Analysis of the Experiences of Coping with Type 1 Diabetes in School; A Teenage Perspective.
REC reference: 12/NS/0014
Amendment number: AM01-1
Amendment date: 6 November 2012

Thank you for submitting the above amendment, which was received on 8 November 2012. It is noted that this is a modification of an amendment previously rejected by the Committee (our letter of 18 October 2012 refers).

The modified amendment was reviewed by the Sub-Committee in correspondence. A list of the members who took part in the review is attached.

Ethical opinion

I am pleased to confirm that the Committee has given a favourable ethical opinion of the modified amendment on the basis described in the notice of amendment form and supporting documentation.

Approved documents

The documents reviewed and approved are:

Document	Version	Date
Email confirmation from Sponsor - Raymond French		6 November 2012
Participant Feedback Invitation Letter	1	24 September 2012
Protocol	2	24 September 2012
Modified Amendment	AM01-1	6 November 2012
Interview Schedules	2	22 November 2012

R&D approval

All investigators and research collaborators in the NHS should notify the R&D office for the relevant NHS care organisation of this amendment and check whether it affects R&D approval of the research.

Statement of compliance

The Committee is constituted in accordance with the Governance Arrangements for Research Ethics Committees and complies fully with the Standard Operating Procedures for Research Ethics Committees in the UK.

12/NS/0014:	Please quote this number on all correspondence
--------------------	---

Yours sincerely

And Irvine

PP **Dr Alex Johnstone**
Chair

Enclosures: List of names and professions of members who took part in the review

Copy to: NHSG R&D Department
Marise Bucukoglu, University of Edinburgh

NRES Committees - North of Scotland (2)

Attendance at Sub-Committee of the REC meeting by correspondence

<i>Name</i>	<i>Profession</i>	<i>Capacity</i>
Dr Georgina Hold	Senior Lecturer - Gastroenterology	Expert
Dr Alex Johnstone	Chair & Senior Scientist in Human Nutrition	Expert

Appendix 2. NHS R & D Permission.

Research and Development

Foresterhill House Annexe
Foresterhill
Aberdeen
AB25 2ZB



Miss Sara Yule
Trainee Clinical Psychologist
NHS Grampian
The Rowan Centre
The Glassgreen Centre
Elgin
IV30 6GQ

Date 09 March 2012
Your Ref
Our Ref 2012GD001

Enquiries to
Extension 53846
Direct Line 01224 553846

Dear Miss Yule

Management Permission for Non-Commercial Research

Ethics Ref: 12/NS/0014

Project title: A qualitative analysis of the experiences of coping with Type 1 Diabetes in School: A Teenager Perspective

Thank you very much for sending all relevant documentation. I am pleased to confirm that the project is now registered with the NHS Grampian Research & Development Office. The project now has R & D Management Permission to proceed locally. This is based on the documents received from yourself and the relevant Approvals being in place.

All research with an NHS element is subject to the Research Governance Framework for Health and Community Care (2006, 2nd edition), and as Chief or Principal Investigator you should be fully committed to your responsibilities associated with this.

It is particularly important that you inform us when the study terminates.

The R&D Office must be notified immediately and any relevant documents forwarded to us if any of the following occur:

- A change of Principal Investigator, Chief Investigator or any additional research personnel
- Premature project termination
- Any amendments – substantial or non-substantial (particularly a study extension)
- Any change to funding or any additional funding

We hope the project goes well, and if you need any help or advice relating to your R&D Management Permission, please do not hesitate to contact the office.

Yours sincerely

A handwritten signature in black ink, appearing to read 'S. Ridge', with a stylized flourish at the end.

Susan Ridge
Non-Commercial Manager

Cc

Appendix 3. Letter of Invitation – Young person.



Recipient name and address

Researcher name and Address
Recruitment reference number
Date

Dear [Recipient]

We are asking if you would join in a research project called **Diabetes and School: Teenage Views**.

With your help we would like to find answers to the question ***“What are the positive and negative experiences for teenagers with Type 1 Diabetes of managing their diabetes within the school environment?”***, so we would like to hear about your own experiences.

You have been contacted to participate because you are aged 13-16 and have had a diagnosis of Type 1 Diabetes for more than 6 months.

You do not have to take part in the research and if you decide not to take part that will not have any impact upon the care you currently receive from the diabetic team.

If you decide to take part in the study you will be invited to come along for one interview session with the researcher who will ask you questions about having Type 1 Diabetes at school. As I am interested in gaining your own experiences of life with diabetes, it would be most helpful to interview you by yourself, without a parent/guardian present in the room.

We have enclosed an information sheet about the study for you to read and discuss with family and friends.

If you would like to take part in the study and have the opportunity to tell us more about your experiences, and your parents are happy for you to do this, please complete the 'opt in slip' below.

Please return the completed slip in the envelope provided it's already got the address and stamp on it (by date). The chief investigator will then contact you by telephone, answer any questions you might have, and arrange a good time to meet with you and complete the interview.

Yours sincerely

Sara Yule
Trainee Clinical Psychologist (Chief investigator)

Appendix 4. Letter of Invitation – Parent/Guardian.



The Parents of Recipient name and
address

Researcher name and
Address

Date

Recruitment reference number

Dear Parents of

My name is Sara Yule and I am a Trainee Clinical Psychologist. I am conducting a study into the experiences of young people with diabetes at school.

We would like to invite your son/daughter to take part in a study about the experiences of adolescents with Type 1 Diabetes within the school environment. Interview questions will investigate young people's positive and negative experiences in school in relation to pupils and staff, as well as the practicalities of managing their diabetes.

It is anticipated that health professionals working in the field of diabetes can use this understanding to tailor information and guidance to school personnel regarding the needs of pupils with Type 1 Diabetes.

The study involves completing about an hour long interview with your son/daughter, asking questions about their experience of life at school with diabetes. As we are interested in gaining your son/daughter's own experience, it would be most helpful to interview them by themselves, without you present in the room. It is expected that this will be a positive experience for your son/daughter, as many young people enjoy having the opportunity to give their personal views.

Enclosed is an information sheet about the study for you to read and discuss with your son/daughter. Please also feel free to contact the researcher to discuss any questions that you may have. Contact details for the researcher can be found on the last page of the information sheet.

If your son/daughter would like to take part in the study and you are happy for them to do this, please complete the 'opt in slip' included and send it to Sara Yule in the stamped addressed envelope provided as soon as possible. She

will then contact you to arrange a convenient time to meet with your son/daughter and complete the interview.

Whilst we would very much appreciate your son/daughter's help they are not obliged to take part and if they decide not to take part, it will not affect the standard of care they receive.

Many thanks for your time.

Sara Yule
Trainee Clinical Psychologist (Chief investigator)

Diabetes and School: Teenage Views.



This is a study being carried out with young people aged 13 to 16 in Moray who have Type 1 diabetes. We are looking for young people to get involved.



Before you decide if you want to join in, this information sheet is to let you know why we are doing the research, and what would happen if you wanted to take part. So please read this leaflet carefully. You can talk to other people like family or friends about it if you want to.



What is the study about?

The aim of this study is to find out about your experiences of managing your diabetes at school – both good and bad. We are also keen to hear how you think staff and other pupils have responded to you having diabetes.

You do not have to take part in this study. It is your decision to get involved.

Why me?

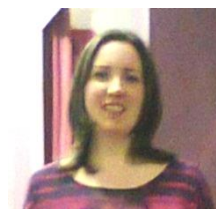
You have been invited to join in because you are at school and have had Type 1 Diabetes for at least 6 months. We would like to hear about your experiences.



What will taking part involve?

If you decide to take part in the study we will ask you to take part in one interview session with Sara Yule who is the psychology researcher.

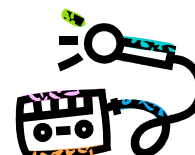
The session will last for about an hour, and will involve answering questions and talking about your experiences.



As we are interested in what it is like for you to have diabetes at school, it would be best if Sara could speak to you by yourself, without your parents in the room.

It is not a test and there are no right and wrong answers.

The session will be audio recorded so that the researcher has a record of all of your answers. Only the researcher will listen to your recorded interview.



Your school will not know that you have decided to take part in the study

What will you do with my answers?

The information given by all of the young people will be analysed to see if there are any common difficulties or good experiences and this information will be put into a report.



The report may include quotes from your interview, but no names will be put into the report, so no one will be able to tell who has said those things.



Will I get to know what you have found out?

If you decide to take part in the study and would like to find out about the results, a letter telling you about what we have learned can be sent to you at the end of the study.

Will taking part help **me** in any way?

We cannot promise that the study will help you directly.

Taking part in this study will give you a chance to speak openly and honestly about what it is like to manage your diabetes at school.

We hope that your answers will help health professionals to better understand young people's experiences with diabetes.

This could also improve the advice given to schools about how to help young people with Type 1 Diabetes to manage their condition.



I would like to take part, what next?

If you want to take part we will ask you to sign to give your assent (agreement to take part).

Because you are aged 16 or under, we will also ask a parent/guardian to sign to give consent for you to take part.



What if I change my mind and do not want to take part?

You can stop taking part at any time during the research without giving a reason. It is ok if you decide to you want to stop, and this will not affect the care you receive from the diabetic team.

What are risks of taking part?

There are no known risks to taking part in this study. However, in the interview I may ask you some questions about how you feel about yourself and how diabetes has affected your life. It may be that thinking about these things makes you feel upset.

We will keep your information in confidence. Any information about you that we have will be stored securely in our department so that nobody else can have access to it.

Before any research goes ahead it has to be checked by a Research Ethics Committee. They make sure that the research is fair. Your project has been checked by the North of Scotland Research Ethics Committee.



Thank you for reading this - please
ask any questions you need to.

Enquiries to: Sara Yule (Trainee Clinical Psychologist)

The Rowan Centre (Mental Health Services for Children and Adolescents)

The Glassgreen Centre

2 Thornhill Drive

Elgin

IV30 6GQ

Telephone: 01343 553111

Appendix 6. Opt-in Slip.

Recruitment reference number:

My parent/guardian and I have read the invitation letter about the study:
Diabetes and School: Teenage Views.

My parent/guardian and I are interested in the study

Young Person:

I want to take part in the study looking at teenagers experiences of diabetes in school.

Parent Guardian name: _____

I am willing for my son/daughter to take part in the study: Diabetes and School; Teenage Views.

If you indicate that your son/daughter is willing to take part, Sara Yule will be in contact shortly to arrange a convenient time to meet with you and your son/daughter.

If you are willing for your son/daughter to be involved please provide contact details so Sara can arrange to meet with you and your son/daughter.

Contact telephone number:

What is the best time to contact you? _____

Appendix 7. Young Person Assent Form.



Young Persons Identification Number for this trial:

Young Persons Assent Form

Diabetes and School: Teenage Views.

Name of Researcher: Sara Yule

Put your
initials
in the boxes below
if you agree

1. I have read and understood the information sheet about the study.
I have been able to think about the information and ask questions.

2. I understand that I do not have to take part in the study. I know that
if I take part that I can stop taking part at any time without having to give a
reason, and that this will not affect my care in any way.

3. I understand and agree that the interview session will be audio recorded.

4. I agree to take part in the study.

When the study it is finished I would like a letter to be sent to me telling me
what the study has found.

Yes / No

Name of Participant:

Date:

Signature:

Name of Person
taking assent:

Date:

Signature:

When completed: 1 for participant; 1 for researcher site file.

Appendix 8. Parent/Guardian Consent Form.



Patient Identification Number for this trial:

Parent/guardian CONSENT FORM

Title of Study: Diabetes and School; Teenage Views

Name of Researcher: Sara Yule

Please initial

the box

1. I confirm that I have read and understand the information sheet for the above study. I have had the opportunity to consider the information, ask questions and have had these answered satisfactorily.

☐

2. I understand that my son/daughter's participation is voluntary and that (s)he is free to withdraw at any time without giving any reason, without his/her medical care or legal rights being affected.

☐

3. I understand and agree that my son/daughters interview session will be audio recorded.

☐

4. I agree for my son/daughter to take part in the above study.

☐

I would like to find out about the results of the study. I would like to receive a letter telling me what the study has found.
Yes / No

Name of Parent/guardian:

Date:

Signature:

Name of Person:
taking consent

Date:

Signature:

When completed: 1 for participant; 1 for researcher site file.

Appendix 9. Semi-structured interview schedule.



Semi-Structured Interview Schedule

Diabetes and School: Teenage Views.

Ice-breaker plus: ask about education (school, year), & engagement in education (attendance, enjoyment), Current age, Diabetic regimen.

Do you know/can you remember when you were diagnosed with diabetes?

What school year were you in when you found out?

Tell me about your experience of having diabetes?

How has diabetes fitted into your school life? (And/or during school hours?) (Invite specific examples)

Who at school knows about your diabetes?

How did other pupils react when they learned that you have diabetes?

How did members of staff react when they learned that you have diabetes?

What is your most positive experience of telling people at school about having diabetes?

What is your least positive experience of telling people at school about having diabetes?

Who at school has been most supportive about your diabetes management? In what way(s) have they helped you?

What has been most helpful to you in managing diabetes in school?

What has been least helpful to you in managing diabetes in school?

Can you attend a diabetic clinic at school?

Is there anything that could make it easier for you to manage diabetes in school?

Prompts - can you tell me a bit more about that? Invite specific examples

Probes – what do you mean by...?

Appendix 10. Example of interview transcript, coding and analysis.

Emerging themes	Transcript	Comments
Supportive People	I: What has been your most positive experience about telling people at school? P: As in teachers or? I: Anybody teachers, friends, classmates...	Difficulty with answering goes to friends first in answer (importance of friends).
Knowledge (wanting is positive)	P: I don't know...my friends didn't...(sigh) they...they kinda...when I was in hospital they came to hospital and visited me and then they kinda...I had a wee book, that was...it was like of diabetes, and it was really simplified language, and they all like when they were sitting beside me had a read of it, and they've all got a...a basic grasp of it and they know what to do. Um, none of the teachers particularly bothered except PE staff who treat me really quite well.	Support from friends when in hospital at diagnosis, friends interested in knowing more and knowing what to do.
Supportive people	I: Oh, right? P: Like, one day last week the teacher that has my chocolate was off and my chocolate was all locked in a cupboard so one of the PE staff actually went into his lunchbox and gave me some of the chocolate out of his, so they're all really nice to me, like they all know me on like a first name basis...really good to me, so that's probably the most positive responses.	Teachers perceived disinterest in general – interest supportive?
Adjusting and accepting ...makes it easier	I: What's been the least positive experience with people at school? P: Erm... there's not a least positive experience, there's not anything too bad. I suppose at the start it got on my nerves, like every single person like if they noticed you would ask you... I: Alright P: It was like multiple questions bombarding you, and that was...that would get annoying, but that settled down awful quickly and everyone just expected it and didn't really notice it was...Um, it was embarrassing sometimes like if a teacher, if we had a cover teacher, and the teacher didn't know, and like if I said I wanted to go to the toilet and they wouldn't let me, then I'd have to say I'm a diabetic can I please go to the toilet, that would...'cause at that time I wasn't overly comfortable with it, so it was...it was quite embarrassing sometimes, but like now I don't bother about it really, and there's been nothing really that's happened really, it's all been ok.	Support from teachers practically helpful. Knowing the young person and accepting their needs and adjusting/ going out of their way to help diabetes to fit feels good to young person.
Stand out/attention from others – not positive		Initially frustrating feeling as though everybody noticing would ask, overwhelming, repetitive (bombarding – attack?).
Repetitive questioning (unhelpful) Knowledge (helps)		Other people getting to know about it/understand helped difficulty to become less of an issue.
Lack of Knowledge (unhelpful – Attention)		Embarrassment being prevented from undertaking diabetes care in front of the class by teacher who did not know (stand out in front of peers/called attention to it).
Adjusting and accepting (becoming more comfortable)		Initially uncomfortable with diabetes and speaking up but get used to it become used to it.

Appendix 11. Example of Supervision Notes.

Supervision Notes

Present: Sara Yule, chief investigator & Dr Melanie Lees, Clinical Supervisor

Discussion:

Initial themes emerging from first transcript

1. Direct knowledge helps
2. Learning about self and diabetes
3. Taking responsibility
4. Lack of knowledge → mismanagement/problems
5. Nurse liaison with schools helps
6. Teachers knowledge
7. Consistency
8. Need support to do what need to do for diabetes management
9. Standing out is problematic (peers)
10. Friends support is important
11. Everybody should learn about diabetes
12. Pave the way (introduce diabetes to people for the young person)

Discussion of themes some fit well together, some surprising themes so discussed sections within transcript supporting the theme, agreement that there was sufficient discussion within the transcript to merit the themes remaining.

Together analysed the themes and discussed initial connections – coalesced into higher order themes:

Knowledge → 1, 2, 4, 6, 11

Support → 8, 10, 12

Standing out → 9

Other themes uncategorised → 3, 5, 7

Knowledge- key issue discussed more than just knowing and being able to act upon it, encompassed understanding, and implications for the young people.

Support – emerging theme, various sources of support discussed, reflected upon the levels of support and the helpfulness of it. Concurred regarding the integration of the 3 themes under the larger heading remained valid.

Discussed nature of the difficulty experienced as a result of standing out because of diabetes.

Plan: Further transcribing to be completed

Analysis of additional transcripts to be undertaken using existing themes as framework and to be discussed at next supervision.

Supervision Notes Example 2

Present: Sara Yule, Chief Investigator & Dr Melanie Lees, Clinical Supervisor

Discussion:

More interviews have been undertaken. Interesting process, discussion and reflection on the interviews...becoming more comfortable with the process and importance of not analysing within the interview process, but listening and responding to the young person in the room.

Additional themes emerging discussed and evidence from transcripts investigated.

- Repetitiveness of the telling
- Becoming used to having diabetes
- Fitting diabetes in
- Becoming more confident in own ability

Discussed if new themes could be integrated into existing higher level themes felt to be separate to the themes and therefore were justified as being in addition, no title given for the theme. Repetitiveness separate to the other emerging themes.

Growing evidence in support of the existing themes was also discussed and determined what was relevant and applicable evidence that fit under the theme, discussed the variety of the experiences within the theme and impact of the actions of others on the experiences.

Plan: continue with the final interviews and transcribing.

Supervision Notes Example 3

Present: Sara Yule, Chief Investigator & Dr Melanie Lees, Clinical Supervisor

Discussion:

Reflection on the outcomes of all of the transcripts.

Discussion of three of the main theme headings:

1. Support
2. Knowledge and Understanding
3. Standing Out

Felt to have sufficiently captured within them evidence that had been gathered with a good level of participant support although with differing opinions and experiences within each of the themes.

Further category entitled 'getting on with it' was discussed; encompassed themes of becoming used to having diabetes, fitting diabetes in, becoming more confident, Taking responsibility, and Consistency. Decided upon discussion that the theme heading was not representative of the breadth of subsumed themes. It was suggested that a better way of encapsulating the evidence was within a theme of adjusting and accepting, a better fit and therefore to take forward in final write up.

Final theme of Over and Over not as strongly evidenced however to be taken forward as an additional result following discussion due to the impact upon the young people who described it.

Ordering of the themes discussed.

‘Support’ highest – reasoning discussed; significant to majority of participants, not just frequency of discussion but its impact upon the young people.

‘Knowledge and Understanding’ next highest; is highly influential on experience especially in the school environment. Significance of the lack of it concerning and negative impact...area for implications for practice discussed as recommendation.

(Consider further in discussion)

‘Standing out’; of personal significance – stage of life, educational impact and health implications discussed. (Potential Psychological perspective to be looked into further).

‘adjusting and accepting’; developmentally relevant, process, how to help?.

Plan: begin to draw conclusions for discussion

Implications for practice and recommendations to be considered further.

Appendix 12. Analysis of study using CASP and IPA evaluation tools.

CASP Evaluation standard	Achieved	Details
Was there a clear statement of the aims of the research?	Yes	Yes - aims set out clearly
Is a qualitative methodology appropriate?	Yes	Appropriate method given aim was to examine lived experience and to gather the views of individuals as experts of their experience.
Was the research design appropriate to address the aims of the research?	Yes	Yes - details choice of IPA which fit with the focus of the study and justified the use of a small sample.
Was the recruitment strategy appropriate to the aims of the research?	Yes - (partially unable)	Describes how sample was selected and contacted, included eligibility criteria. No discussion about how participants decided whether or not to take part as that was not possible to establish.
Were the data collected in a way that addressed the research issue?	Yes	Setting of the data collection detailed, justified method of collection by semi-structured interview and method of recording.
Has the relationship between researcher and participants been adequately considered?	Yes	Researcher relationship was considered and discussed as was the location for the interview.
Have ethical issues been taken into consideration?	Yes	Ethics sought and achieved, informed consent was taken and right to withdraw discussed
Was the data analysis sufficiently rigorous?	Yes (partially)	Stepwise process for analysis was used as per IPA book Smith et al., 2009. Evidence was sufficient to support theme conclusions and contradictory data was included. - Additional information on processes to assure rigor has been included in the methodology and results.
Is there a clear statement of findings?	Yes	Clear statement of findings was presented with differing experiences illustrated and discussed in relation to the aims of the study.
How valuable is the research?	Yes	Value of the research was discussed and potential areas of future interest considered.

Evaluation of the study using the IPA quality evaluation guide Smith (2011).

Criteria for acceptability	Achieved & Detail
Clearly subscribes to the theoretical principles of IPA: it is phenomenological, hermeneutic and idiographic.	Adheres to IPA principles is phenomenological and interpretive, attempting to understand the meaning of the individuals experiences.
Sufficiently transparent so reader can see what was done	Methodology clearly set out and following IPA guide Smith et al., 2009.
Coherent, plausible and interesting analysis	Analysis was reported to be interesting and coherent by clinical supervisor, diabetes specialist nurse and school teacher.
Sufficient sampling from corpus to show density of evidence for each theme: N1-3: extracts from every participant for each theme; N4-8: extracts from at least three participants for each theme	Uses evidence from at least 3 participants for each of the themes.

Appendix 13. Invitation to participate in post study feedback interview.



Researcher Address

Reference No:

Date

Dear Participant,

I would like to thank you again for taking part in the study ***Diabetes and School: Teenage Views***. I have now completed the interviews and some interesting themes have emerged.

The themes are:

- Support
- Knowledge and Understanding
- Standing Out
- Adjusting and Accepting
- Over and Over

To make sure that I have represented your views properly I would like to conduct telephone interviews with one or two participants to discuss responses to the themes.

If you would be willing to take part in a short telephone interview to discuss the results and tell me what you think **please contact me at 01343 553111** to arrange a suitable time for the discussion by DATE

Many thanks for your time.

Sara Yule
Trainee Clinical Psychologist (Chief investigator)

Appendix 14. Author Guideline: Pediatric Diabetes

Pediatric Diabetes - Author Guidelines - Wiley Online Library

Page 1 of 9

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Pediatric Diabetes

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